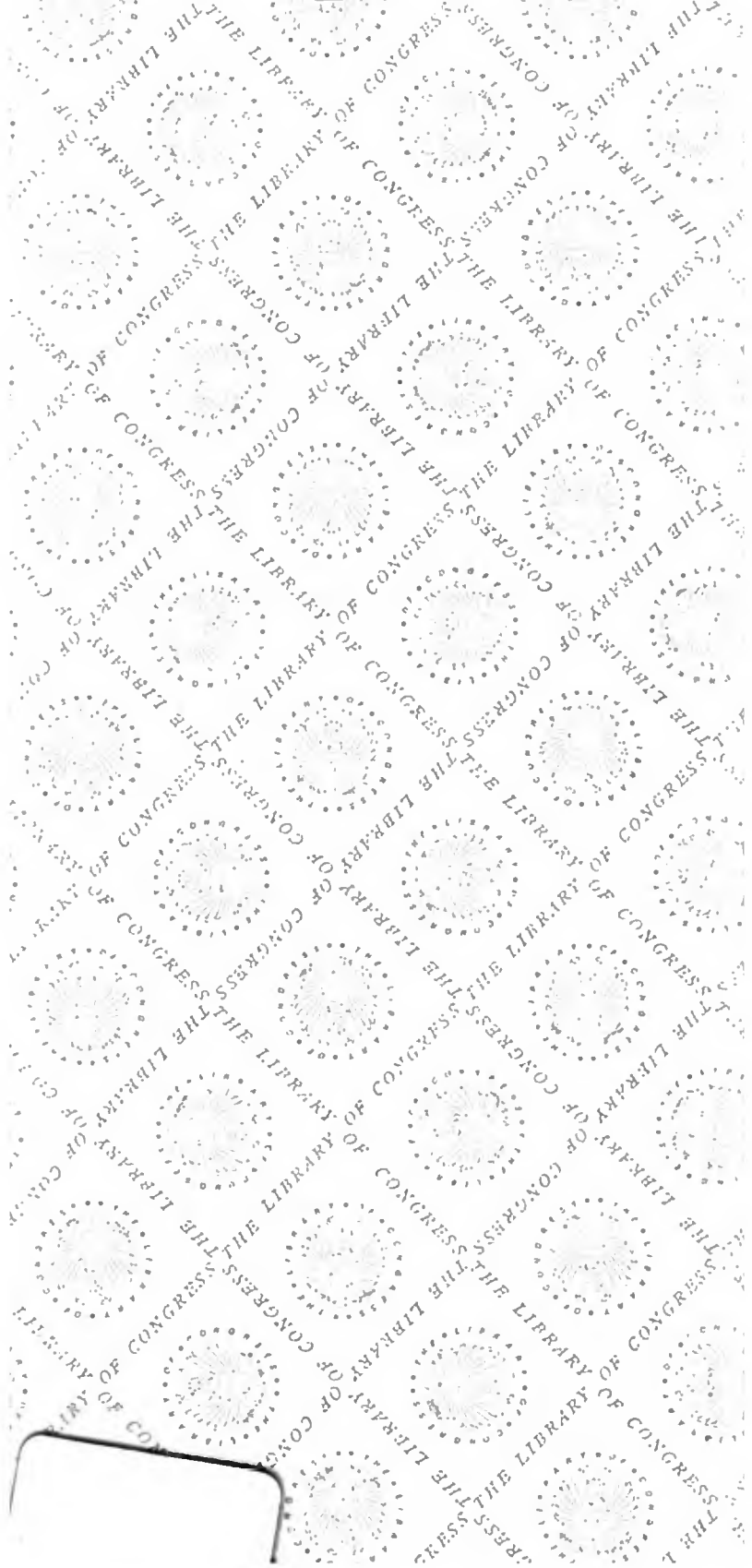
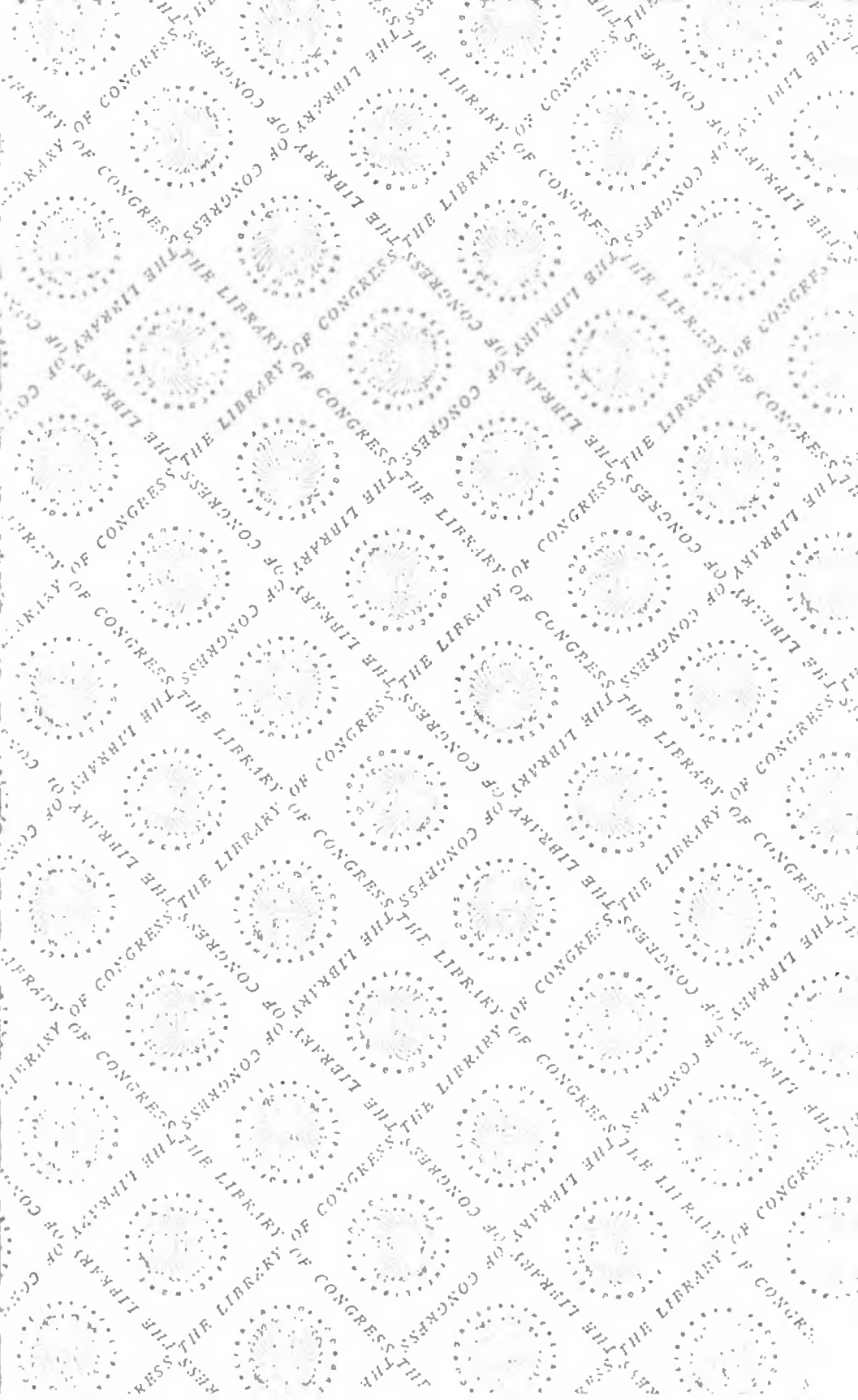


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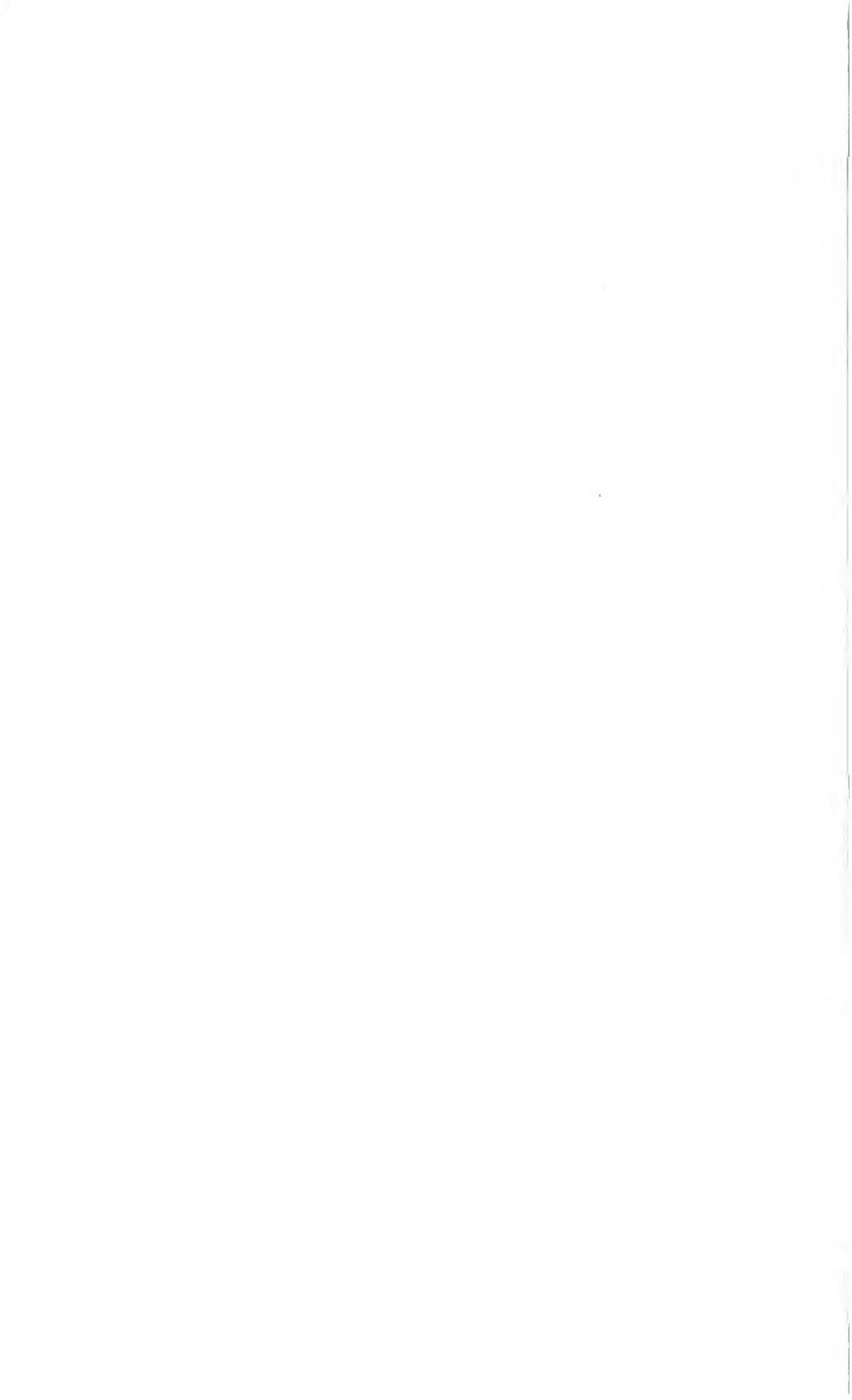
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# ADVISORY COMMISSION ON EPILEPSY AND ITS CONSEQUENCES

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HEARING

BEFORE THE

SUBCOMMITTEE ON  
PUBLIC HEALTH AND ENVIRONMENT.

*United States Congress* OF THE *House.*

COMMITTEE ON  
INTERSTATE AND FOREIGN COMMERCE. ✓  
HOUSE OF REPRESENTATIVES

NINETY-THIRD CONGRESS

SECOND SESSION

ON

**H.R. 13405**  
(and all identical bills)

BILLS TO PROVIDE FOR THE ESTABLISHMENT OF A NA-  
TIONAL ADVISORY COMMISSION TO DEVELOP A NATIONAL  
PLAN FOR THE CONTROL OF EPILEPSY AND ITS  
CONSEQUENCES

\_\_\_\_\_  
AUGUST 12, 1974

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**Serial No. 93-95**

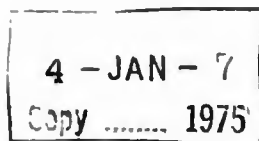
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## CONTENTS

Text of—	Page
H.R. 13039.....	2
H.R. 13405.....	2
List of identical bills to H.R. 13405 introduced after hearing.....	6
Report of the Office of Management and Budget, Executive Office of the President, on H.R. 13405.....	7
Statements of—	
Attitudes, information, and education panel:	
Autry, James, editor-in-chief, Better Homes and Gardens, Des Moines, Iowa.....	111, 134
Furman, John, broadcast standards, Cox Broadcasting Corp., Atlanta, Ga., and president, Georgia Chapter, Epilepsy Foundation of America.....	111, 113
Gallup, George, Jr., president, American Institute of Public Opinion.....	111, 142
Simonds, Scott K., Dr. P.H., professor, Health education, and director, health education program, University of Michigan School of Public Health.....	111
Steitz, Marjorie, Bethesda, Md.....	111, 127
Consumers panel:	
Belcher, Mrs. Allison Logan, Portland, Oreg.....	63, 69
Mittendorf, Miss Martha, Alexandria, Va.....	63
Root, Mrs. Cathy, Miami Lakes, Fla.....	63, 64
Williams, Cal, Culver City, Calif.....	63, 66
Epilepsy Foundation of America panel:	
Daly, David D., M.D., Ph. D., president, International League Against Epilepsy.....	32, 52
Funk, Paul E., executive vice president, Epilepsy Foundation of America.....	32, 162
Grass, Ellen R., president, International Bureau for Epilepsy.....	32, 44
Health, Education, and Welfare Department:	
Beinstein, Dr. Lionel M., Director, Office of Program Operations, Office of the Assistant Secretary for Health, Department of Health, Education, and Welfare.....	7
Schulhof, Trina, Office of Legislation, Department of Health, Education, and Welfare.....	7
Tower, Dr. Donald, Director, National Institute of Neurological Diseases and Stroke, National Institutes of Health, Department of Health, Education, and Welfare.....	7
Medical panel:	
Daly, David D., M.D., Ph. D., president, International League Against Epilepsy.....	86
Sahs, Adolph L., M.D., professor emeritus, and former chairman, Department of Neurology, University of Iowa College of Medicine.....	86
Van Pelt, John, M.D., attending pediatrician, Maine Coast Memorial Hospital, and chief, medical services, Elizabeth Levison Development Center.....	86
Wilder, B. Joe, M.D., chief, neurological services, Veterans Hospital, Gainesville, Fla., professor of neurology, University of Florida, and director, Epilepsy Research Laboratory, University of Florida Medical Center.....	86, 88
Mink, Hon. Patsy T., a Representative in Congress from the State of Hawaii.....	79

## Statement of—Continued

## Social and rehabilitation panel:

Arangio, Anthony J., Ph. D., associate professor, School of Social Work, University of Texas at Arlington, and head, community planning and administration, University of Texas at Arlington.....	Page 98, 103
McAllister, Jack, director, Division of Retardation, Department of Health and Rehabilitative Services, State of Florida.....	98, 107
Russell, Iiarold, Chairman, President's Committee on Employment of the Handicapped.....	98
Sinick, Daniel, Ph. D., professor of education, director, rehabilitation counselor education program, and editor, Vocational Guidance Quarterly, George Washington University.....	98, 101
Van Pelt, John, M.D., attending pediatrician, Maine Coast Memorial Hospital, and chief, medical services, Elizabeth Levison Development Center.....	81
Additional information submitted for the record by—	
American Medical Association, Ernest B. Howard, M.D., executive vice president, letter dated August 20, 1974, to Chairman Rogers...	165
American Nurses' Association, Inc., Eilcen M. Jacobi, Ed. D., R.N., executive director, letter dated August 19, 1974, to Chairman Rogers.....	164
Autry, James, editor-in-chief, Better Homes and Gardens, Des Moines, Iowa, attachment to prepared statement, article entitled "What You Should Know About Epilepsy, Parkinson's Disease, Multiple Sclerosis, and Other Brain Disorders".....	136
Blair, Frank, LHD, NBC News, letter dated August 7, 1974, to Chairman Rogers.....	164
Dominick, Hon. Peter H., a U.S. Senator from the State of Colorado, letter dated August 9, 1974, to Congressman Peter Kyros.....	80
Epilepsy Foundation of America:	
Aid to families with dependent children.....	60
Measuring cost of epilepsy.....	58
Representative Kyros talks about epilepsy and a national plan—ESM annual meeting, excerpts from Mr. Kyros' speech of May 23, 1974.....	42
Furman, John, broadcast standards, Cox Broadcasting Corp., Atlanta, Ga., and president, Georgia Chapter, Epilepsy Foundation of America, attachments to Mr. Furman's prepared statement:	
Annual services report, Georgia Chapter, EFA.....	116
"Epilepsy—The Misunderstood Illness," series of articles by Jean Tyson.....	120
Gallup, George, Jr., president, American Institute of Public Opinion, attachment to prepared statement; "A Survey of Public Attitudes Toward Epilepsy in 1974 With an Indication of Trends Over the Past 25 Years".....	145
Health, Education, and Welfare Department:	
Funds available to support epilepsy-related activities in DHEW—nine areas surveyed.....	10
"Genetic Studies in Clinical Epilepsy—Discussion".....	18
NINDS obligations for information and education on epilepsy..	13
Steitz, Marjorie, Bethesda, Md., attachment to prepared statement, article entitled "Epilepsy: Why the Secrecy, The Shame?".....	132
Talbot, Hon. Gerald E., State representative, State of Maine.....	163

# ADVISORY COMMISSION ON EPILEPSY AND ITS CONSEQUENCES

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MONDAY, AUGUST 12, 1974

HOUSE OF REPRESENTATIVES,  
SUBCOMMITTEE ON PUBLIC HEALTH AND ENVIRONMENT,  
COMMITTEE ON INTERSTATE AND FOREIGN COMMERCE,  
*Washington, D.C.*

The subcommittee met at 10 a.m., pursuant to notice, in room 2123, Rayburn House Office Building, Hon. Peter N. Kyros presiding [Hon. Paul G. Rogers, chairman].

Mr. KYROS. The subcommittee will please be in order.

Good morning, ladies and gentlemen, and welcome to this subcommittee session. Let me begin by saying that it is both a great pleasure and an honor for me, as original sponsor of H.R. 13405, to chair these hearings. I am particularly pleased that the distinguished chairman of our Subcommittee on Public Health and Environment, Mr. Rogers, is able to join us for a

So at this point I w

Mr. ROGERS. I am f  
so many in this room  
Congress some propo  
epilepsy. I think the b  
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optimistic that this co

So I am delighted to be here with you, Mr. Kyros, and thank you. Mr. Kyros. Thank you, Mr. Chairman.

The legislation we are considering today, H.R. 13405, to create a 1-year National Commission on Epilepsy and Its Consequences, was first introduced by me on February 26 of this year. It was subsequently reintroduced with the cosponsorship of every member of this subcommittee, and I am very pleased to announce that I will be reintroducing the bill with the cosponsorship of an additional 53 Members of the House.<sup>1</sup> These Members come from both political parties and represent districts throughout the United States, demonstrating the broad-based support this legislation has.

I know that we are anxious to receive the testimony of the witnesses assembled here, and I might add that I think we have an outstanding and very distinguished group of men and women to hear from. I will, therefore, make no lengthy remarks at this time. May I ask, however, that through the day, which promises to be a long one, witnesses submit their written statements and paraphrase their remarks and we will include their entire statement in the record. This will give the maximum amount of time possible for discussion.

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<sup>1</sup> See p. 7, for a listing of sponsors and bills subsequently introduced.

At this time let me provide for the record, so that we can begin to define the problem, a brief definition.

Generally, though, the word is applied to a number of disorders of the nervous system, centered in the brain, so it is more exact to say "the epilepsies." The term comes from the Greek word for "seizures" and seizures of one kind or another are the primary characteristics of all forms of epilepsy. Seizures can range all the way from a slight momentary lapse of consciousness to a major convulsion.

The seizure is caused by a buildup of excessive electrical charges in some nerve cells of the brain which causes a temporary loss of muscular control. The buildup of electrical charges is caused by a lesion or scar or injury to these nerve cells of the brain. That lesion can result from many different causes such as defects in the brain; brain injury before, during and after birth; head wounds; chemical imbalances; poor nutrition; childhood fevers; some infectious diseases; brain tumors; and some poisons.

One point that I want to make very clear is that head injury from automobile accidents and other types of head injuries are one of the primary causes of epilepsy in adults, but sometimes the cause cannot be found.

Without objection the text of H.R. 13039 and H.R. 13405 and an agency report thereon shall be placed in the record at this point.

[The bills and report referred to follow:]

[H.R. 13039, introduced by Mr. Kyros on February 26, 1974, and H.R. 13045, introduced by Mr. Kyros (for himself, Mr. Rogers, Mr. Satterfield, Mr. Preyer, Mr. Symington, Mr. Roy, Mr. Nelsen, Mr. Carter, Mr. Hastings, Mr. Heinz, and Mr. Hudnut) on March 12, 1974.

are identical as follows:]

## A BILL

To provide for the establishment of a national advisory commission to develop a national plan for the control of epilepsy and its consequences.

*Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,*

### SHORT TITLE

SECTION 1. This Act may be cited as the "National Commission on Epilepsy and Its Consequences Act".

### FINDINGS

SEC. 2. The Congress finds that—

(1) there are approximately four million Americans with the neurological disorder known as epilepsy, and

1 thousands of addiitonal cases arise each year as the result  
2 of head trauma alone;

3 (2) epilepsy is a major health problem for which no  
4 satisfactory solution has been developed, placing an eco-  
5 nomic, social, and psychological burden upon individuals,  
6 families, and the Nation as a whole;

7 (3) a problem of this magnitude affects our entire  
8 society even though the social stigma associated with  
9 epilepsy encourages its victims to conceal their  
10 affliction;

11 (4) medical knowledge and technical methodologies  
12 now available are not being applied to this problem  
13 on a broad scale, with balanced interdisciplinary action;  
14 and

15 (5) effective management of epilepsy demands the  
16 concerted attention of many disciplines—medical and  
17 health education, social and rehabilitation services, and  
18 public assistance.

19 NATIONAL COMMISSION

20 SEC. 3. (1) The Secretary of Health, Education, and  
21 Welfare (hereinafter referred to as the "Secretary"), after  
22 consultation with the advisory council to the National In-  
23 stitute on Neurological Diseases and Stroke appointed under  
24 section 342 of the Public Health Service Act, shall appoint  
25 a National Commission to determine the most effective

1 means of finding the cause of and cures and treatments for  
2 epilepsy, and to develop a national plan for the control of  
3 epilepsy and its consequences. Such study and investiga-  
4 tion shall give particular emphasis to the need for additional  
5 financial support by the Federal Government and the means  
6 by which the Federal Government can best participate in  
7 this effort.

8 (2) The Secretary shall appoint to the Commission  
9 (A) three members of the advisory council referred to in  
10 paragraph (1), and (B) six other individuals, who by  
11 reason of experience or training in the medical, social, or  
12 educational aspects of the epilepsies, are specially qualified  
13 to serve on such Commission; to include a representative  
14 consumer of services to be designated by the National Epi-  
15 lepsy Foundation of America, and two representatives of  
16 the National Advisory Council on Developmental Disabilities.  
17 The members of the Commission shall select a Chairman  
18 from the members appointed under clause (b) of the pre-  
19 ceding sentence. Members of the Commission shall be en-  
20 titled to receive the daily equivalent of the annual rate of  
21 basic pay in effect for grade GS-18 of the General Schedule  
22 for each day (including traveltime) during which they are  
23 engaged in the actual performance of duties vested in the  
24 Commission. While away from their homes or regular places  
25 of business in the performance of services for the Commission,

1 members shall be allowed travel expenses, including per  
2 diem in lieu of subsistence, in the same manner as persons  
3 employed intermittently in the Government service are  
4 allowed expenses under section 5703 (b) of title 5 of the  
5 United States Code.

6 (b) The duties of such Commission shall be to—

7 (1) consult with concerned organizations with the  
8 purpose of stating the problems and defining the gaps  
9 in and barriers to existing health care delivery systems;

10 (2) make a comprehensive study of the state of the  
11 art of medical and social management of the epilepsies  
12 in the United States;

13 (3) investigate and make recommendations con-  
14 cerning the proper roles of the Federal and State gov-  
15 ernments, and the national and local public and private  
16 agencies in research, prevention, identification, treat-  
17 ment, and rehabilitation of persons with epilepsy;

18 (4) develop a comprehensive national plan for the  
19 control of epilepsy and its consequences based on the  
20 most thorough, complete, and accurate data and infor-  
21 mation available on the disorder; and

22 (5) transmit to the Secretary for transmittal to the  
23 President and the Congress a final report (which shall  
24 include recommendations for such legislation as the

1 Commission determines is necessary) not later than one  
 2 year after the date of enactment of this Act.

3 (c) The Secretary shall provide such administrative  
 4 support services for the Commission as it may request.

5 (d) Each department, agency, and instrumentality of  
 6 the executive branch of the Federal Government, including  
 7 independent agencies, shall furnish to the Commission, upon  
 8 the request of its Chairman, such information, services, per-  
 9 sonnel, and facilities as the Commission deems necessary to  
 10 carry out the purposes of this section.

11 (e) The Commission shall cease to exist thirty days  
 12 after submitting its report.

EXECUTIVE OFFICE OF THE PRESIDENT,  
 OFFICE OF MANAGEMENT AND BUDGET,  
 Washington, D.C., September 3, 1974.

HON. HARLEY O. STAGGERS,  
 Chairman, Committee on Interstate and Foreign Commerce,  
 House of Representatives  
 Washington, D.C.

DEAR MR. CHAIRMAN: This is in response to your request of March 15, 1974 for the views of this Office on H.R. 13405, a bill "To provide for the establishment of a national advisory commission to develop a national plan for the control of epilepsy and its consequences."

In testimony before your Committee on August 13, 1974 the Department of Health, Education, and Welfare stated its reasons for recommending against enactment of H.R. 13405.

The Department states that it supports the objectives of H.R. 13405, but views the statutory establishment of a new Commission as an inappropriate mechanism to deal with issues related to epilepsy. The Department notes that it is already engaged in strong and effective program efforts to address the problem of epilepsy and that it has called a national conference to discuss the problems and needs of persons suffering from this disease.

For the reasons stated by the Department of Health, Education, and Welfare in its testimony, we recommend against enactment of H.R. 13405.

Sincerely,

WILFRED H. ROMMEL,  
 Assistant Director for Legislative Reference.

[The following is a list of bills and sponsors which were introduced after the day of hearing and before the printing of the hearing:]

**LIST OF IDENTICAL BILLS TO H.R. 13405 INTRODUCED AFTER HEARING**

- H.R. 16403, introduced by Mr. Cederberg on August 13, 1974;  
 H.R. 16404, introduced by Mr. Kyros (for himself, Mr. Boland, Mr. Corman, Mr. Roybal, Mr. Pritchard, Mr. Wyman, Mrs. Grasso, Mr. Ellberg, Mr. Conyers, Mr. Podell, Mr. Drinan, Mr. Murtha, Mr. Froehlich, Mrs. Burke of California, Mr. Lehman, Mr. Matsunaga, Mrs. Collins of Illinois, Mr. Pepper, Mr. Murphy of New York, Mr. Nix, Mr. Yates, Mr. Mazzoli, Mr. Fauntroy, Mr. Edwards of California, and Mr. Sarbanes) on August 13, 1974;  
 H.R. 16407, introduced by Mr. Kyros (for himself, Mr. Melcher, Mr. Burgener, Mr. Moakley, Mr. Hechler of West Virginia, Mr. Tiernan, Mr. Roe, Miss Holtzman, Mr. Murphy of Illinois, Mrs. Hansen of Washington, Mr. Brown of Michigan, Mr. Conte, Mr. Grover, Mr. Fuqua, Mr. Hicks, Mr. King, Mr. Collier, Mr. Thompson of New Jersey, Mr. Hosmer, Mr. Ford, Mr. Winn, Mrs. Mink, Mr. Ketchum, Mr. Broyhill of Virginia, and Mr. Edwards of Alabama) on August 13, 1974;  
 H.R. 16408, introduced by Mr. Kyros (for himself, Mr. Patten, Mrs. Holt, Mr. Rallsback, Mr. Benitez, Mr. Harrington, Mr. Vander Jagt, Mr. Quile, and Mr. Stokes) on August 13, 1974;  
 H.R. 16829, introduced by Mr. Kyros (for himself, Mr. Slkes, Mr. Yatron, Mr. Cleveland, and Mr. Cotter) on September 24, 1974;  
 H.R. 16979, introduced by Mr. Esch, on October 1, 1974;  
 H.R. 17420, introduced by Mr. Kyros (for himself and Mr. Glenn) on October 16, 1974; and  
 H.R. 17426, introduced by Mr. Brinkley on October 17, 1974.

Mr. KYROS. At this time I would like to begin this hearing by introducing the representatives from the administration. Our principal witness is Dr. Lionel Bernstein, Director of the Office of Program Operations, Public Health Service.

Dr. Bernstein, welcome to the committee.

**STATEMENT OF DR. LIONEL M. BERNSTEIN, DIRECTOR, OFFICE OF PROGRAM OPERATIONS, OFFICE OF THE ASSISTANT SECRETARY FOR HEALTH, DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE, ACCOMPANIED BY DR. DONALD TOWER, DIRECTOR, NATIONAL INSTITUTE OF NEUROLOGICAL DISEASES AND STROKE, NATIONAL INSTITUTES OF HEALTH; AND TRINA SCHULHOF, OFFICE OF LEGISLATION**

Dr. BERNSTEIN. Thank you, Mr. Chairman.

It is a pleasure for me to be here today to present the views of the administration on H.R. 13405, a bill to establish a National Commission on Epilepsy. We appreciate the opportunity to discuss with you our activities and recommendations relating to one of the Nation's serious health problems.

**DESCRIPTION OF LEGISLATION**

This legislation would establish a national commission to develop a plan for the control of epilepsy and its consequences. The nine members of the Epilepsy Commission would be appointed by the Secretary with three from the National Advisory Neurological Diseases and Stroke Council and six others especially qualified by training or ex-

perience in the medical, social or educational aspects of the epilepsies. One of the six would be designated by the Epilepsy Foundation of America, and two would be representatives of the National Advisory Council on Developmental Disabilities.

The Epilepsy Commission would (1) consult with concerned organizations to present problems and define gaps and barriers in existing health care delivery systems; (2) make a study of the state of the art of medical and social management of the epilepsies in the United States; (3) study and make recommendations concerning roles of Federal and State governments and private agencies in research, prevention, identification, treatment and rehabilitation of persons with epilepsy; (4) develop a comprehensive national plan for control of epilepsy and its consequences; (5) transmit to the Secretary for transmittal to the President and Congress a final report (including legislative recommendations) not later than 1 year after date of enactment.

Mr. Chairman, although the Department believes the intentions of the sponsors of this legislation are laudable, we oppose the statutory creation of the proposed Commission. Such a Commission is neither necessary nor desirable for reasons I will outline.

Before discussing the specific reasons for our opposition to H.R. 13405, however, I would like to describe for you the scope of the problem presented by epilepsy and our current programs in this area.

#### EPILEPSY

Epilepsy, a common manifestation of many diseases of the central nervous system, constitutes a major health problem. The disorder is marked by sudden and periodic lapses of consciousness and various types of involuntary motor activity.

The National Institutes of Health estimates about 2 million people are afflicted, although there are other estimates as high as 4 million. Some authorities believe these estimates may be too low, since restrictions on obtaining employment, driver's licenses, insurance, et cetera, would encourage individuals to keep their conditions a secret. In 1974 the Epilepsy Foundation of America estimates the cost of the epilepsies at \$4.25 billion. Although epilepsy affects persons of all ages, the majority are children and young adults. The stigma long associated with epilepsy can limit the earning power of persons who are so affected, and can lead to self-deprecation and feelings of social inadequacy. Due to recent medical developments, however, most patients enjoy relative freedom from seizures.

During the first half of the century many significant advances aroused hope for an early solution to the problems of the epileptic person. Among these advances were improved diagnostic methods, including electroencephalography and special X-ray procedures, as well as improved methods of treatment using anticonvulsant drugs and surgery. Basic research on epileptic mechanisms has also led to a greater understanding of brain function.

Progress continues to be made in areas of basic research. However, the clinical application of research findings has not kept pace with research developments in epilepsy, as in many other diseases. Unfor-

tunately, epilepsy is often inaccurately diagnosed and inadequately managed. These deficiencies may be more prevalent in low-income families.

The comprehensive health insurance plan submitted by the Department, however, will make substantial inroads on this problem by removing financial barriers to needed care.

#### CURRENT HEW PROGRAMS

In addition to its proposal for national health insurance financing, the Department has had a long history of activities relating to epilepsy both in the areas of research and services.

#### RESEARCH ACTIVITIES

As you know, the National Institutes of Health is the DHEW agency primarily concerned with biomedical research. Within NIH the National Institute of Neurological Diseases and Stroke (NINDS) has been involved with research activities in epilepsy since its formation in the early 1950's. The 1975 NINDS budget contains \$6.4 million for research on epilepsy. Since 1966 the Epilepsy Advisory Committee has been productive in defining the state of the art in specific research areas and in stimulating interdisciplinary research efforts to bear on the problems of the epilepsies. Other areas of interest to NINDS that are relevant to understanding epilepsy have been information storage and retrieval, basic research in neurophysiology, basic mechanisms of the epilepsies, experimental models of epilepsy, epidemiology of epilepsy, laboratory evaluation of antiepileptic drugs, serum level determination of antiepileptic drugs, pharmacology of antiepileptic drugs, and surgery for epilepsy.

NINDS intramural interest has centered on surgical management of the epilepsies and relationships between head injuries and the epilepsies. The extramural program supports basic research in the epilepsies through the awarding of grants. Projects range from animal models to neurochemical and neurophysiological studies of epileptic neurons to drug and surgical treatment of human patients.

The collaborative and field research program has been particularly involved, through contracts, with the evaluation of potential antiepileptic drugs, drug pharmacology, basic mechanisms, and epidemiology of the epilepsies. Among the many achievements of this program has been the approval for the first time in 14 years of a drug for chronic use in epilepsy. This task required skillful coordination with representatives of the pharmaceutical industry, universities, and the FDA. This success has spurred further development of additional antiepileptic drugs by other researchers.

#### SERVICE ACTIVITIES

The Department administers a variety of health service activities of benefit to epileptic people.

Services for the child with epilepsy developed impetus with the crippled children's services program in the 1950's. In 1961 progress in research into the diagnosis, treatment, and long-term management of

neurologic problems had reached the point where widespread application of findings was possible. From January 1962 through June 1970 the neurological and sensory disease control program attacked this problem, particularly through funding of multidisciplinary diagnostic and treatment centers.

The Rehabilitation Services Administration has major responsibilities for epileptic people administered through its vocational rehabilitation programs and its developmental disabilities program. The Vocational Rehabilitation Service estimates that in fiscal year 1974 approximately \$10 million was spent for rehabilitation services to epileptic people. In addition to research and demonstration grants to improve services to epileptic people, considerable emphasis has been placed on training rehabilitation counselors and others who can serve epileptic people. Other programs administered by the Rehabilitation Services Administration include those under the authority of the Developmental Disabilities Act, which was amended in 1970 to include services to epileptic people.

Other departmental agencies currently involved with aspects of health services for epilepsy are the Social Security Administration, FDA, Health Services Administration, and Health Resources Administration. We will conduct a survey of the funds available to support epilepsy-related activities in HEW and we will submit that result for the record.

[The following information was subsequently received for the record:]

FUNDS AVAILABLE TO SUPPORT EPILEPSY-RELATED ACTIVITIES IN DHEW—9 AREAS SURVEYED

Agency	Activity	Fiscal year 1974 in round numbers
NINDS.....	Research.....	\$6,000,000
SSA.....	Social security benefits.....	6,250,000
SRS.....	Vocational rehabilitation.....	10,000,000
SSA.....	Supplemental security income (estimated).....	57,000,000
SSA.....	Medicaid (estimated).....	10,000,000
SSA.....	Medicare (estimated).....	10,000,000
HSA.....	Crippled children's program (estimates not possible).....	
OE.....	Special education (estimates not possible).....	
SRS.....	Aid to families with dependent children (estimated).....	10,000,000
Total.....		109,250,000

Note: Where estimates were made they were with qualifications that there is absolutely no way to prove or disprove the figures because the way payments are broken down there are no provisions for setting epilepsy aside as a special entity.

COORDINATION OF ACTIVITIES

Dr. BERNSTEIN. The Department has had a series of committees whose responsibilities included coordination of epilepsy activities.

In 1966 the Secretary's Advisory Committee on the Epilepsies was formed with authority for appointment of members delegated to the Assistant Secretary for Health and Scientific Affairs. In July 1971 the Committee was restructured and established as the NIH Epilepsy Advisory Committee with the purpose of advising NINDS on its research programs to develop methods to prevent and control seizures.

In sum, Mr. Chairman, the Department supports a variety of effective and coordinated activities that are directed at all facets of the

problem of epilepsy, from research to services. We believe that, after considering the many other competing health priorities, they are receiving support at a level commensurate with current opportunities and the size of the problem.

#### LEGISLATION

Returning to the legislation before you today, the central purpose of H.R. 13405 would be to develop a national plan for the control of epilepsy and its consequences through the mechanism of a National Commission. Although we recognize the importance of epileptic problems, the Department does not believe that a statutorily established commission is an appropriate mechanism to deal with these issues.

In light of the recently expressed congressional and public interest in this problem, the Assistant Secretary for Health has proposed to call a national conference of persons and organizations most familiar with the areas of difficulty to which H.R. 13405 addresses itself. Department staff have already begun planning for such a conference. We plan to use the recommendations of this conference to assess the possibilities for other effective efforts that the Department could undertake.

The functions and activities of the Commission envisioned by H.R. 13405 would more appropriately be accomplished by the proposed conference. The conference participants will thoroughly discuss both the research and the service aspects of the epilepsy problem. This proposed conference will identify any gaps in and barriers existing to health care delivery, outline the state of the art of medical and social management of the epilepsies, and recommend the most profitable areas for future Government and private involvement in the problem. We will, of course, need to consider the conference's product in light of what the appropriate Federal, State, local, and private roles should be.

The Department, therefore, strongly objects to this legislation which would create a rigidly structured and slow-moving Commission. Among other things, it would not allow for input from all possible sources. The Department's forthcoming conference will provide a more immediate and much preferable forum for airing the problems of persons suffering from epilepsy.

In conclusion, let me repeat that while we commend the intent of the bill before you today, the Department is already engaged in strong and effective program efforts to address the problem of epilepsy. The proposed legislation is therefore unnecessary, especially in the light of the Assistant Secretary's forthcoming conference on epilepsy.

That concludes my formal statement, Mr. Chairman. My colleagues and I would be glad to answer any questions you or members of your committee have.

Mr. KYROS. Thank you, Dr. Bernstein.

At this time may we identify who is with you at the witness table.

Dr. BERNSTEIN. Dr. Tower is the director of the National Institute of Neurological Diseases and Stroke, and Mrs. Triana Schullhof is from the Department's Office of Legislation.

Mr. KYROS. Dr. Bernstein, before I turn to questions from the committee, I would like to say although I admire you very much, of

course, and admire the work you have done—and it has been a steady source of enrichment in my own attitude toward health, the things people like yourself do—it is kind of unsettling and dismaying to have you come in with such negative attitude toward this simple bill and to display before us all the conferences and future conferences that you are going to set up to take care of a problem which you define as possibly afflicting 2 million people, maybe 4 million people. In other words, sitting here in the Federal Government, you and I, do not know how many people are involved.

So without much more I will turn to the chairman of our committee, Mr. Rogers.

Mr. ROGERS. Thank you very much.

I believe you say the estimated cost to the Nation is a little over \$4 billion.

Dr. BERNSTEIN. Yes, sir.

Mr. ROGERS. And anywhere from 2 to 4 million people are affected. Would that be about right? I notice you say that we are not doing a good job in clinical application of present knowledge, is that true?

Dr. BERNSTEIN. I believe that is a generic problem in the sense that there must always be a gradient of information and capability as one moves from the centers where new information is developed out toward the periphery. As you know, Dr. Edwards and his staff is in a major way addressing the problems of attempting to integrate the various activities of the Department to find ways to facilitate and hasten the transfusion or diffusion of new information into practice.

I stated that there was a lag and there is necessarily one whenever there are centers where in-depth profound new findings are being generated, so in that sense necessarily as accomplishments occur in given centers, there is a temporary lag in the diffusion of those findings into widespread practical use.

Mr. ROGERS. I presume this is rather accelerated in epilepsy; the problem is compounded in epilepsy?

Dr. BERNSTEIN. I believe one of the difficulties in being quantitative is the absence of data, as was previously referred to. One of the Department's efforts at the moment is to establish better data systems, particularly in cooperation with local communities and States, so that we will have a much better handle on the specific categories of disease as they occur and as they are handled.

Mr. ROGERS. In your statement on page 4, you say, "Epilepsy is often inaccurately diagnosed and inadequately managed."

Dr. BERNSTEIN. I think that is a reflection of the diffusion lag. In centers where the greatest expertise lies, there is a capability to address those individual patient problems in a fashion that is of higher quality than would be available in the "periphery."

Perhaps Dr. Tower would care to make an additional comment on that.

Dr. Tower. Mr. Rogers, as you know, we have undertaken in the last year a feasibility study of a comprehensive epilepsy program, which is addressed to this precise problem in which we expect to bring together, in a research center setting, all the other services and ancillary needs that the epileptic requires for total care. We expect this study to be completed in approximately a year, and the results of it

will allow us to design a definitive program in which we can set up these centers in various parts of the country.

This is aimed at the precise problems you have identified and should markedly increase our ability to get this information out into the community to the general practitioners and other paramedical personnel that need it.

Mr. ROGERS. What efforts have been made by HEW in the area of general education, information to the general public about epilepsy, in order to remove the stigma? Are we doing much; have we spent money; do we have people working?

Dr. TOWER. Yes, sir. We have done a considerable amount of work in regard to this, both at professional and lay levels.

Mr. ROGERS. What part of the budget is devoted to education of the public on epilepsy?

Dr. TOWER. I cannot give you precise figures, but I can provide it for the record.

Mr. ROGERS. Can you give us an estimate?

Dr. TOWER. The order of a couple of hundred thousand dollars from our budget is going into this each year.

Mr. ROGERS. Let us have this figure for the record.

[The following information was received for the record:]

#### NINDS OBLIGATIONS FOR INFORMATION AND EDUCATION ON EPILEPSY

The NINDS information and education program on epilepsy includes pamphlets for the public in both English and Spanish, a yearly special report to Congress (at their request) on the present status of research, on short film, exhibits from time to time primarily for scientific audiences, answers to public inquiries, and a series of monographs, bibliographies, abstracts, reprints, and books to inform the scientific community of all current advances in research and treatment. This table shows obligations for Fiscal Year 1973 and Fiscal Year 1974.

#### NINDS OBLIGATIONS FOR INFORMATION AND EDUCATION ON EPILEPSY

	GPD printing cost	Information office preparation cost	Epilepsy section preparation cost
<b>Fiscal year 1973—\$143,064 total:</b>			
Epilepsy, Hope Through Research (reprint).....	\$4,587	\$500	-----
Epilepsy, Hope Through Research (Spanish) (revised).....	2,104	600	-----
Printing of "Research Profiles 1972".....	364	1,833	\$450
Film, "The Absence Seizure".....			5,000
Monograph No. 1—A Review of Basic and Clinical Research.....	880	30	-----
Monograph No. 14—The Epidemiology of Epilepsy.....	11,000	2,740	10,000
Blood Level Determinations of Antiepileptic Drugs.....	268	30	-----
Bibliograph No. 2—Blood Levels.....	800	30	2,000
Epilepsy Abstracts.....			50,000
Methodology Workshop.....			3,500
Reprints and distribution of papers produced by Epilepsy Section.....			2,750
Experimental Models of Epilepsy (textbook).....			24,000
<b>Fiscal year 1974—\$103,164 total:</b>			
Reprinting—Monograph No. 12.....	250	40	-----
Reprinting—Publication List.....	50	40	-----
Epilepsy Abstracts.....			53,000
Neurosurgical Techniques in Epilepsy (textbook).....			17,000
Reprints of papers produced by Epilepsy Section.....			2,750
50-year Epilepsy Bibliograph.....			20,000
Printing of "Research Profiles 1973".....	164	2,000	500

Mr. ROGERS. I notice, Dr. Bernstein, you say Assistant Secretary of Health is going to call a national conference of persons and organiza-

tions most familiar with epilepsy—how many people would participate, do you think?

Dr. BERNSTEIN. I believe that, perhaps, Dr. Tower and his staff could give some more information. I don't know how definitive our answer to that question would be.

Dr. TOWER. For a conference of this sort, we would estimate that we would probably need somewhere between 50 and 100 people.

Mr. ROGERS. How long would it last?

Dr. TOWER. Probably a week.

Mr. ROGERS. Where would it be held?

Dr. TOWER. Probably here.

Mr. ROGERS. You would have them make recommendations?

Dr. TOWER. Yes, sir, that is correct.

Mr. ROGERS. What budget would you plan to have?

Dr. TOWER. The budget would probably require something in the order of up to \$50,000 depending on how far the people being brought here would be coming from and that sort of thing.

Mr. ROGERS. Do you have to pay their travel?

Dr. TOWER. Yes, sir, that is correct.

Mr. ROGERS. Per diem here?

Dr. TOWER. Yes, sir.

Mr. ROGERS. Then the cost?

Dr. TOWER. Yes, sir.

Mr. ROGERS. When is it slated to be held?

Dr. TOWER. The date has not been set. This would depend upon the availability of the people once the invitations have been extended. I would think we would have to plan it for about 8 months from now. That is the usual timing.

Mr. ROGERS. Then maybe by the time we set up this Commission and get it going, it would not be much of a time element difference, would there, because this requires a report within a year. I presume it would take some time to get this group together that you speak of, writing their reports and so forth. So, I expect that would be about 1 year don't you imagine?

Dr. TOWER. I believe we could have a report much sooner than that, sir, because once the conference is held, the information can be collated and put together quickly.

Mr. BERNSTEIN. A good deal of the work in such a conference is accomplished by staff and the members of the conference ahead of time, so the staff papers are created and that allows functional accomplishment of the kinds of things to which you refer.

Mr. ROGERS. So, you think a 1-week conference would be as good as 1 year's study by experts; is that what you are telling us?

Dr. TOWER. Well, Mr. Rogers, the Commission would have to call conferences of its own. The number of people on the Commission would be insufficient, and they would not have sufficient time to develop this information themselves.

I would refer you to the experiences of the Multiple Sclerosis Commission, in which they brought together between 50 and 60 experts, who met at least three times for several days each over the period of the life of that Commission, in order to develop the information they needed.

Mr. ROGERS. That is what I think may be needed, but I won't pursue that argument now.

Mr. KYROS. Mr. Nelsen.

Mr. NELSEN. Thank you, Mr. Chairman.

I just want to comment that, many times when there is obviously a need for putting some emphasis on a program or a problem, bills like this are introduced to prod a bit, to move faster, to do more things. But in testimony that we have received on other pieces of legislation, it is obvious that the inclination on the part of the Congress is to set up another commission, another commission, another commission, to the extent that I think we have several hundred commissions. At this point we seem to dissipate the possibility of success toward a goal by making it top heavy with commissions.

But I guess we must say that, frankly, sometimes it would appear that the only way we can get the emphasis and get that push is to introduce bills. If there is a better way, we want to find it. I have found this: That in some of our health legislation we have various programs that are presently on the books and everybody wants to maintain their personal identity with every program, to the point where you almost have battles going on between activities that also dissipate the possibility of success.

Now, I just want to say this; while we do not like to be at odds with the way things are handled sometimes it appears necessary to prod a bit, and I believe the purpose of this bill is to get some emphasis and more activity in this field.

I have had some personal experience with epilepsy in the family, and I know how terrible it is. I hope by some manner or means we may, through research, find some cures.

I have nothing further to say at this point, but I want to think the witnesses. It is not always easy to be a witness. I have been one myself, so I want to say thank you to all of you who are here.

Mr. KYROS. Mr. Preyer.

Mr. PREYER. Thank you, Mr. Chairman.

I want to commend Mr. Kyros for bringing this to our attention. I want to thank you, Dr. Bernstein, for your statement, which certainly serves a useful purpose in bringing together all of this information about epilepsy about the different departments that are all concerned with epilepsy.

Let me ask a few questions that may seem a bit elementary.

You state that the majority of people suffering from epilepsy are children and young adults. Is epilepsy something that you eventually outgrow or, once you are afflicted with it, do you always have it?

Dr. TOWER. Mr. Preyer, a number of children will outgrow epilepsy. The precise percentage is really unknown, because our data gathering mechanisms are imperfect in this regard, but, certainly, a fair percentage of people who develop epilepsy in later childhood or early adult life will continue to have it all their lives. This is the reason why it presents such a problem from a social and economic point of view. They must continue to take chronic medication for all their lives.

Mr. PREYER. It is a hereditary problem?

Dr. TOWER. Only in part. There is some evidence that some cases are hereditary, but the majority are acquired usually through some injury to the brain.

Mr. PREYER. So, it is not similar to sickle-cell anemia, where it is clear that certain genes are responsible?

Dr. TOWER. No, sir.

Mr. PREYER. You mentioned the new drugs that are available for treating epilepsy and that most patients enjoy relative freedom from seizures. Do we actually have drugs that can control epilepsy for say, a majority of people? I think you said most patients.

Dr. TOWER. Yes, the number that is usually quoted is 60 percent of the patients enjoy complete freedom from seizures while on drugs. The other 40 percent have partial or no control.

We are in the process of developing further drugs which we hope will attack this latter percentage of the patients.

Mr. PREYER. Drugs can now control 60 percent?

Dr. TOWER. Approximately, yes, sir.

Mr. PREYER. And you hope that new research will control 100 percent?

Dr. TOWER. That is our goal, yes, sir.

Mr. PREYER. So then, it will be important, as you mentioned elsewhere, if you have the drugs that can control epilepsy, that patients be able to pay for it?

Dr. TOWER. That is correct, yes, sir.

Mr. PREYER. How much of a problem is that now? Is there any estimate of the number of people for whom drug therapy would be effective and yet they cannot pay for it?

Dr. TOWER. The cost per year is \$50 to \$500 per patient. We do not have an accurate estimate of how many cannot afford this. But we do know this a very substantial problem for the epileptic patient population, primarily because many of them are unable to hold jobs or to earn an adequate income, and, therefore, this level of cost is much more serious to them than it would be to you or me.

Dr. BERNSTEIN. That would be addressed in the National Health Insurance Program, because the administration's position is to cover medications. I think this is a demonstration of how some general approaches do address and satisfy needs in individual categorical illnesses.

Mr. PREYER. Do these drugs allow for any loosening of the restrictions on drivers' licenses and employment opportunities?

Dr. TOWER. In many cases, yes, sir, but as you realize, much of the legislation is at the local-State level, and therefore, there will be inequities across the country unless these are taken care of State by State and community by community.

Dr. BERNSTEIN. Part of the educational effort in the Institute in other programs is to enlighten the general population so as not to impose on these individuals the inequity of attitudes that has been existent in the past.

Mr. PREYER. Let me just ask one other question.

You mentioned surgical management of the epilepsies and the rela-

tionship between head injuries and epilepsies. Are their surgical solutions available for these patients?

Dr. TOWER. In a certain number of cases, yes, sir. It depends upon whether the process in the brain is sufficiently localized so that it is amenable to surgical attack. It is what we call focal epilepsy, in which the area of the brain which is discharging abnormally is localized into a focus that can be identified by brain waves and that sort of thing and is in an area which is accessible to the surgeon.

Under these circumstances, it can be taken out, and in at least 50 or 60 percent of the cases operated on, this results in a cure. Unfortunately, the majority of the cases do not occur in this fashion. They are more generalized and are not amenable to surgery.

Mr. PREYER. That would be a very small proportion of cases?

Dr. TOWER. That is correct, yes sir.

Mr. PREYER. Thank you, Mr. Chairman.

Mr. KYROS. Dr. Carter.

Mr. CARTER. Thank you, Mr. Chairman.

Epilepsy, of course, has been known throughout the ages. Do you remember some of the famous men in history who suffered from this disease? Julius Caesar, was he not one? Napoleon is said to have been one. What do you think are the causes of epilepsy?

Dr. TOWER. Dr. Carter, the causes of epilepsy are a great many different causes. A few are hereditary in nature.

Mr. CARTER. Really, have you found that very often?

Dr. TOWER. Only in a relatively small proportion of the cases.

Mr. CARTER. I would like to see your figures on that.

[Testimony resumes on p. 27.]

[The following information was received for the record:]

## Discussion

### GENETIC STUDIES IN CLINICAL EPILEPSY\*

JULIUS D. METRAKOS AND KATHERINE METRAKOS

We live because we have enzymes. Everything we do—walking, thinking, reading these lines—is done with some enzymatic process.—ERNEST BOREK

In their assessment of modern molecular biology as it applies to the epilepsies, McKhann and Shooter pointed out that enzymes are proteins which have been coded and synthesized by genes. By this token, Ernest Borek could have said, "We live because we have genes."

In the study of disease at the molecular and developmental levels, any lines of demarcation that may have existed previously all but disappear between heredity and environment as etiological factors. If genes are involved in everything we do and if heredity and environment interact and cannot be clearly separated, it is not surprising that genes have been implicated in the most frequently occurring of constitutional diseases, including heart disease, cancer, diabetes, and the epilepsies.

From the geneticist's point of view, it is not presumptuous to state that the most basic of the mechanisms of the epilepsies is the minute gamete and the genes which it carries from one generation to the next. There will be no attempt made here to outline basic principles of genetics and various modes of inheritance; these may be found in any standard textbook of human genetics such as *Genetics in Medicine* by Thompson and Thompson [26]. Instead, the discussion will be limited to: (1) certain basic concepts and mechanisms of which the genetic epileptologist must be aware in his search for genetic factors in the epilepsies and (2) that which the committee for this volume referred to as an original contribu-

tion expected of each discussant. Hopefully, these two additions will serve suitably as adjuncts to the contributions of McKhann and Shooter, to help underscore the basic biochemical genetics concepts presented.

#### SEARCH FOR GENETIC FACTORS IN THE EPILEPSIES

The genetic epileptologist, in his search for genetic factors in the epilepsies, may think and proceed along certain avenues.

##### *Clinical and Genetic Heterogeneity*

First of all, it must be appreciated that the epilepsies constitute a highly heterogeneous group of diseases, that the heterogeneity is not only clinical but also genetic. Genetic heterogeneity refers to different genetic situations, both at the chromosomal and genic levels, which may be capable of producing similar clinical pictures (phenotypes) as far as seizure patterns are concerned. For example, we know of a chromosomal disease, the D1 trisomy, where part of the syndrome is minor motor seizures and where the EEG frequently shows atypical spike-wave complexes [25]. Many hereditary diseases also affect the brain whose genes produce seizures as part of their pleiotropic effect. Examples of these are autosomal dominant tuberose sclerosis, autosomal recessive galactosemia, and sex-linked recessive hydrocephalus. Many other examples may be found in Pratt's *The Genetics of Neurological Disorders* [20] and in McKusick's *Mendelian Inheritance in Man* [12]. Of primary interest here is whether part of this genetic heterogeneity is due to specific *epilepsy per se* genes, capable

\* This review article based on investigations supported by PHS Research Grant NB00706-14 from National Institute of Neurological Diseases and Stroke. *Basic Mechanism of the Epilepsies*, "Genetic Studies in Clinical Epilepsy", Ed. Jasper, Ward, and Pope, Boston: Little, Brown & Co., 1969, pp. 700-708.

of producing epilepsy alone with no other obvious clinical symptomatology.

### *Familial and Genetic Epilepsy*

When a well-defined clinical form of epilepsy is distinguished, the first question to investigate is whether it is familial. Familial means simply whether near relatives of an affected individual are similarly affected more often than near relatives of a comparable unaffected individual. This step is not as simple as it sounds since numerous biases may creep in and distort the answer. The first problem is to set criteria for *affected* and *unaffected*. If the genes involved result in variable severity (expressivity), then it is essential to decide at which point of severity and at which level of examination a near relative will be considered as affected similarly to the patient (proband). Is one convulsion sufficient? Are borderlands of epilepsy to be included? Is an epileptiform EEG without clinical seizures sufficient? Does a specific aminoaciduria with no other signs or symptoms indicate the presence of a single dose of a recessive pathological gene (heterozygous carrier)?

These and other biases have caused and continue to cause considerable confusion in the literature. A more detailed account of some of these has been given elsewhere [14]. However, when these biases are minimized and investigation is properly controlled, it is generally found that the prevalence of individuals with a history of seizures or cerebral dysrhythmias or both, is higher among near relatives of epileptics than among near relatives of nonepileptics.

Since familial predisposition does not necessarily mean that the condition is genetic, other investigations are needed to establish that genes are indeed involved. Pedigree, twin, and sibling studies have supported the conclusion that resistance or susceptibility to epilepsy in general is under genetic control. Unfortunately, at the present time our knowledge concerning these genes is very limited. For example, we know little if anything about such matters as the following.

*Mode of Inheritance.* Although the mode of inheritance is known for many rare cerebral diseases where epilepsy is part

of the syndrome, for the commoner forms of epilepsy, the inheritance pattern remains unclear and seemingly complex. If these forms of epilepsy are due to interaction of two or more genes, which is the case with common diseases, the answer would be very difficult to obtain. Even if it is due to a single pathological gene, the answer may be complicated by phenomena of variability of expression and age of onset and lack of penetrance. The fact that in *centrencephalic* epilepsy there is an optimum age at which the *centrencephalic EEG trait* can be demonstrated (that is, an aspect of lack of penetrance) made it difficult for a long time to realize that the major gene in this form of epilepsy is an irregular, autosomal, dominant gene [16]. How many modifying genes may be involved still remains unclear.

*Gene Frequency and Mutation Rate.* When a gene has been identified and its mode of inheritance is known, several other questions concerning it are then raised. What is the relative frequency of the pathological allele to its normal allele? The answer to this question will provide an estimate of the number of affected individuals and of the number of carriers for any particular recessive form of epilepsy. In this context, the rate at which the normal allele mutates to its pathological form and selective factors becomes important. Except for very few hereditary cerebral diseases mentioned above, nothing is known about gene frequency and mutation rate of epilepsy genes.

*Phenocopy.* When an environmental factor produces a clinical picture closely resembling that produced by a gene, the affected individual is referred to as a phenocopy. In the epilepsies, of course, it is important to establish whether environment or heredity is the primary etiological factor. Both type of treatment and what is said in genetic counseling would depend on this distinction. It is of interest to note here that whether a phenocopy results from an environmental agent (for example, trauma or febrile disease) may well depend on threshold genes controlling resistance or susceptibility of the individual. This is another example of the futile attempt to separate environmental and genetic factors.

**Linkage and Association.** If a gene exists, it must occupy a locus on a particular chromosome. Genes whose loci are on the same chromosome show linkage relationships with one another. At the moment we know of no such linkages between epilepsy genes and marker genes, for example, blood groups. It is important to differentiate between linkage and association. For example, if migraine headache, criminality, suicide, and psychosis are more apt to appear among family members of epileptics than in the general population, this would be a mere association, and no genetic linkage should be implied. (Incidentally, such an association between the conditions mentioned and epilepsy has not, in the opinion of the authors, been established.)

**Mode of Gene Action.** In recent years, biochemical genetics has become the most fundamental and most important aspect of genetics, that branch of genetics which deals with how genic DNA produces its ultimate effect. This topic, amply reviewed by McKhann and Shooter, will not be expanded other than to point out that in the epilepsies, seizure as an end product of a gene is undoubtedly very far removed, by many steps, from the primary product of the gene. As suggested by McKhann and Shooter, it may well be that the end product of the gene is formation of an abnormal protein and the seizure is a far-removed neurophysiological consequence. Wide as this gap may be, it is of utmost importance that it be bridged and that intermediate steps become known. It is a sad commentary that although more is known about the genetics of the erythrocyte than about any other differentiated cell of the human body, the reverse is probably true about the neuron. The task of isolating and characterizing proteins specific to the nervous system is just beginning.

**Gene Regulation.** For the sake of simplicity, discussion so far has been in terms of single epilepsy genes of different categories. However, when it is recalled that no gene acts solely by itself but is dependent upon the whole genotype, probably some 10,000 gene pairs, it is unnecessary to mention that biochemical products of each gene interact, directly or indirectly, with biochem-

ical products of all other genes of the individual. Modern gene concepts state that all major genes have not only pleiotropic effects but that their action is delicately balanced by a number of controlling genes. Some of the controlling genes act as inducers, while others act as inhibitors. Several adjacent genes concerned with the same synthetic process, with a *switch* gene at one end, and a regulator gene elsewhere, are in a state of dynamic equilibrium—the *operon*. Whether epilepsy operons exist, or whether operons exist at all in man, has not been established; but it is clear that with common diseases of man, such as epilepsy, in addition to major genes there are a number of modifying genes resulting in multifactorial inheritance or (if a threshold is involved) quasi-continuous variation. Thus, although a single major gene may be responsible for the *centrencephalic EEG trait*, a number of other genes may be controlling such factors as its variability in age of onset, sex distribution, and severity into typical and atypical.

#### *Balanced Polymorphism*

When the genetic structure of a population is such that several forms of a gene (alleles) are maintained in various but specific frequencies, such a population is referred to as exhibiting balanced polymorphism. Of such a polymorphic population for a particular type of genetic epilepsy, several questions could be asked. Why is the disease so common? What is the relative fertility of affected and unaffected individuals? What are natural and artificial selection pressures? Do genetic carriers show hybrid vigor? Are there any racial or ethnic differences? At the moment there are no answers to any of these questions.

#### *Animal Studies*

In a review of comparative genetics in mammals, Nachtsheim [18] lists 40 hereditary diseases of mammals of which counterparts are also found in man. Epilepsy is one of these diseases. Sidman et al. [24] have cataloged no less than 90 neurological mutants in inbred strains of mice. At least 15 of these exhibit epileptic seizures. What a wealth of material is here for the clinical

epileptologist to pursue parallel animal studies!

The complexity of the genetic mechanism has been demonstrated in the case of audiogenic seizures in mice. It has been found that not only is susceptibility to audiogenic seizures hereditary but also the ability to recover [5]. Furthermore, genes responsible for susceptibility and for recovery segregate independently from one another. More recently Meier [13], Rauch [21], and others [9, 23] have shown association between phenylalanine metabolism and susceptibility to audiogenic seizures in mice. Finding an inhibitor of phenylalanine hydroxylase in *dilute* mice (that is, the susceptible strain) suggests that seizures may result from accumulation of phenylalanine metabolites which have been shown to inhibit decarboxylases. In particular, 5-hydroxytryptophan decarboxylase is inhibited [28]. This enzyme, it will be recalled, is responsible for synthesis of serotonin, the substance which is selectively concentrated in certain brain regions, for example, limbic system. Inasmuch as phenylketonuria and seizures are also found together in man, parallel studies between man and other mammals become essential and should prove most productive.

#### *Therapy and Pharmacogenetics*

The present treatment of epilepsy has been described as the *brute force* approach (surgery) and the *trial-and-error* approach (anticonvulsant therapy). These two approaches will undoubtedly continue to serve the epileptic well for many years to come. However, if certain forms of epilepsy can be traced to genes, then an understanding of their biosynthetic pathways becomes essential for a more scientific program of therapy. Just as genetic blocks (absent enzymes) at specific points in the biosynthetic pathways have been identified in phenylketonuria and galactosemia, so too, in genetic forms of epilepsy, it should be possible to identify enzymatic accumulations or deficiencies. If intermediate substances are accumulating, an understanding of their biochemical nature and position in the biosynthetic pathway would make their removal possible. If the deficiency is due to

an absent enzyme, then at least theoretically, substitution is possible. Recently Hagberg [8] reported on a group of epileptic children with disturbed tryptophan metabolism who were treated with vitamin B<sub>6</sub>.

The term pharmacogenetics, first used by Vogel in 1959 [27], denotes genetic variation of response to drugs. Pharmacogenetics, therefore, is a special aspect of therapy. Genetically determined variations of response to several drugs are now known [6]. For example, it has been well established that the rate of isoniazid metabolism in man is controlled by an autosomal pair of genes. Similar studies have been conducted with such drugs as the muscle relaxant, suxamethonium, with sensitivity to primaquine, and with psychotherapeutic drugs such as the phenothiazines. In all these studies, evidence for genetically determined variations has been found. References to these and other studies may be found in Kalow's *Pharmacogenetics. Heredity and the Response to Drugs* [11], where three of the nine chapters are devoted to heritable factors recognized in man through the use of drugs.

It is conceivable and highly likely that response to some anticonvulsant drugs may be under the control of genes. Such a finding would answer the present puzzling question of why, in two seemingly identical clinical cases of epilepsy, one responds well to a given anticonvulsant to which the other remains resistant.

#### *Genetic Counseling*

An ultimate objective in any genetic investigation of man is the transfer and application of genetic knowledge to genetic counseling situations. If I marry, what is the risk that my children will be epileptic as I am? I have an epileptic child, what is the risk that my next child will also be epileptic? The answers to these questions have been discussed elsewhere [17] in connection with *centrencephalic* epilepsy.

If accurate, empirical-risk figures exist, then genetic counseling can be given with confidence. However, it is unlikely that reliable, empirical-risk figures for different classes of relatives can be determined with-

out knowledge and appreciation of the questions considered under the above five headings.

#### ORIGINAL CONTRIBUTION TO MONOGRAPH

Investigations conducted in the last 15 years have added substantially to the conclusion that hereditary factors are implicated in the etiology of the epilepsies. The results of pedigree, electroencephalographic, twin, animal, and biochemical studies by many investigators have compounded the evidence. Thus the problem is no longer whether or not genes are important in the epilepsies, but rather (1) to identify which genes are acting in which of the epilepsies, and (2) to determine which of these genes may be common to more than one type of epilepsy. Because of its significance, only the second question will be considered here, by reviewing briefly four different but related studies. For simplicity, in all four studies, observations will be confined mainly to siblings of four different types of *epileptic* probands. Although significant differences have been demonstrated between brothers and sisters in one of these studies, for the purpose of this discussion this separation will not be made.

##### *Spike-Wave Epilepsy* (383 Siblings)

Evidence has been presented elsewhere [15, 16] supporting the hypothesis that the EEG showing a relatively good background pattern but with interspersed paroxysmal, bilaterally synchronous bursts of 2.5–3.5 cycles per second (cps) spike-wave complexes is inherited as an autosomal dominant trait, that additional factors, environmental and genetic, interact to precipitate the clinical seizures.

In trying to keep up with recommended changes in terminology, we have, unfortunately, referred to this type of epilepsy in the past as both *centrencephalic* and *epilepsy of subcortical origin*. This means being guilty of contributing to confusion which exists presently regarding the neurophysiological significance of generalized, bilaterally synchronous spike-wave discharges.

For clarification, before proceeding further, an individual is said to have the *spike-wave EEG trait*, if (1) at any time his electroencephalogram shows bursts of paroxysmal, bilaterally synchronous spike-wave complexes occurring rhythmically at a frequency of 2.5–3.5 cps; (2) his record shows a relatively good background pattern and no localizing features; and (3) the trait is obtained spontaneously in the resting record and/or during hyperventilation, and/or during photic stimulation. (Intermittent photic stimulation is carried out with eyes closed at frequencies of 3, 15, 18 alpha, 20 and 25 flickers per second for 6–8 seconds; and at intensity, full, 16.) In other words, several levels of penetrance are considered when deciding whether or not the trait is present. An individual with the trait may or may not have a history of clinical seizures. It should also be pointed out that an individual may exhibit the trait with activation only in one record and spontaneously in the resting record at another time. Thus, approximately 85 percent of probands who usually have several EEGs show the trait in the resting record, approximately 10 percent show the trait with hyperventilation, and 5 percent with photic stimulation. On the other hand, with siblings who usually have only one EEG, only approximately 60 percent show the trait in the resting record; the remainder show the trait either with hyperventilation (35 percent) or with photic stimulation (5 percent).

The studies to be reported here simply attempt to estimate prevalence of the spike-wave EEG trait in siblings of different groups of epileptic probands. Whether this type of EEG originates from only subcortical or only cortical or from both mechanisms is beyond our competence to decide; the polemics are accordingly left to those better fortified to reach a conclusion. Whether or not the EEGs are *over-read* so that prevalence of positive EEGs is higher than it should be is of importance and of concern. However, if this type of subjective error is of the same order of magnitude and in the same direction in the control EEGs of siblings of nonepileptic probands, then our concern is lessened. Since EEGs are read

without prior knowledge of which group they belong to, dangers of this type of bias are minimized.

In the study referred to [15, 16], approximately 37 percent of the siblings of probands with spike-wave epilepsy have the spike-wave EEG trait, compared with 5 percent of comparable controls (Fig. D24-1). For other types of cerebral dysrhythmia, there is no essential difference between the experimental and control groups.

It is clear from the distribution curve that age has an important bearing on whether the EEG trait will be present in the siblings (Fig. D24-2). The trait is not fully developed at birth, but its prevalence

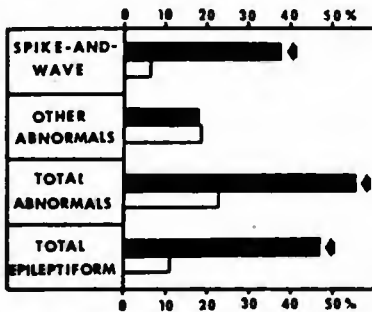


FIG. D24-1. EEG abnormalities in siblings of probands with spike-wave epilepsy. (Arrows =  $p = 0.02$ .)

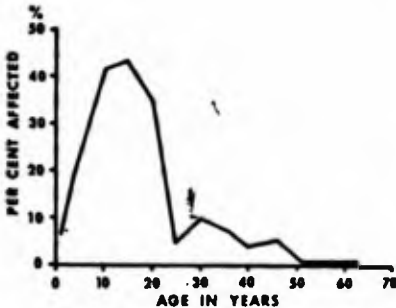


FIG. D24-2. Influence of age on spike-wave EEG trait. (Up to about age 20 years, distribution is based mainly on siblings; after that, based mainly on parents. However, both classes of relatives have a coefficient of relationship of  $r = 0.5$ .)

risks rapidly, so that in the age group of 5-15 years more than 40 percent of the siblings show the trait. For older age groups, the trait tends to disappear and by 40 years of age it is very seldom present, as evidenced by low prevalence in the parents. This higher prevalence of paroxysmal, bilaterally synchronous spike-wave discharges has been found in siblings of at least three other groups of probands with clinical seizures.

#### Febrile Convulsions (147 Siblings)

By observing certain strict criteria, Escala, one of our colleagues, obtained EEGs of siblings of children who developed brief, generalized convulsions in association with fever for the first time between the ages of 6 months and 5 years.

Prevalence of EEG abnormalities among the siblings is significantly higher than among siblings of comparable control probands (Fig. D24-3). It is of interest that approximately 21 percent of siblings of the experimental group had the spike-wave EEG trait.

#### Probands with Focal EEG (127 Siblings)

Changing concepts regarding focal epilepsy prompted a study to test the hypothesis that a familial *convulsive tendency*, as expressed in the EEG, may be an underlying factor in this form of symptomatic epilepsy. In order to avoid subjective interpretations, probands were chosen on the

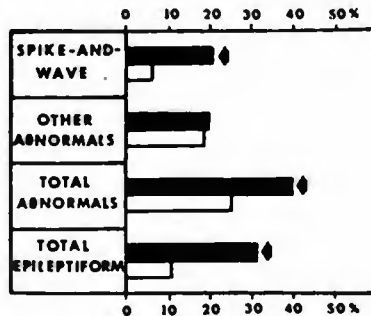


FIG. D24-3. EEG abnormalities in siblings of probands with febrile convulsions.

basis of the single objective criterion of having a focal EEG abnormality; however, surgical intervention was not indicated in any of the probands chosen.

Prevalence of abnormal EEGs among siblings of the focal group is significantly higher than among siblings of a control group (Fig. D24-4). More specifically, prevalence of individuals with the spike-wave EEG trait is significantly higher in the experimental than in the control group. Prevalence of cerebral dysrhythmias among siblings of probands with a focal EEG abnormality is approximately the same as that reported above for siblings of probands with spike-wave epilepsy; however, distribution of types of abnormalities is different.

*Probands Treated Surgically for Focal Epilepsy (63 Siblings)*

Presently, Eva Andermann, another of our colleagues, is studying families of epileptics who have been operated on for focal epilepsy at The Montreal Neurological Institute. To date only 48 families have been studied and EEGs have been taken on only 63 siblings; however, it is already apparent that on the whole, prevalence of EEG abnormalities among the siblings, parents, and offspring of epileptic probands is significantly higher than among the same class of relatives of the control group (Fig. D24-5).

When siblings are considered separately (Fig. D24-6), it is found that only approxi-

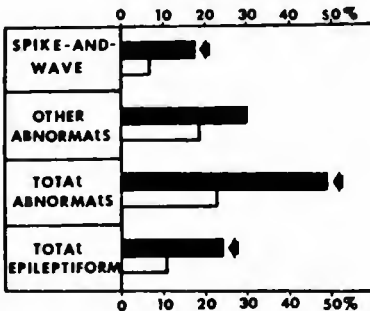


FIG. D24-4. EEG abnormalities in siblings of probands with focal EEG change irrespective of any other findings.

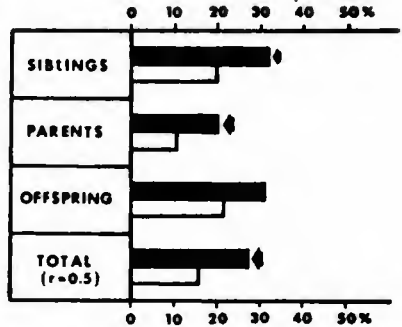


FIG. D24-5. EEG abnormalities in siblings, parents, and offspring of probands operated on for focal epilepsy.

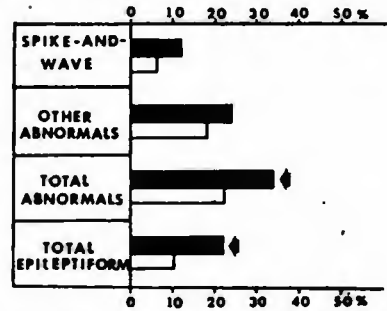


FIG. D24-6. EEG abnormalities in siblings of probands operated on for focal epilepsy.

mately 10 percent have the spike-wave EEG trait. This prevalence is far smaller than for the other three studies; with the small numbers involved, it is not significantly different from that found in controls. However, an explanation that accounts for most of this difference is that the mean age of siblings of this group is much higher (22 yr) than that of the other three groups (6-8 yr). This point has been discussed in more detail elsewhere [2].

The four studies are summarized on the basis of percentage of siblings showing the spike-wave EEG trait (Fig. D24-7). In each of these studies, whenever higher prevalence of epileptiform EEG abnormalities is found in siblings of epileptic groups than in siblings of control groups,

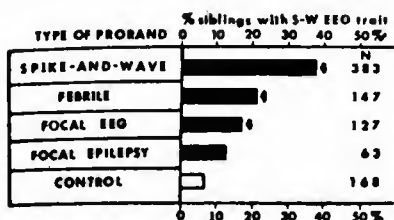


FIG. D24-7. Spike-wave EEG trait in siblings of 4 different types of probands with seizures compared with siblings of nonepileptic probands.

most of the elevation appears to be due to higher prevalence of individuals with the spike-wave EEG trait.

This observation suggests that perhaps several of the *epilepsies*, including febrile convulsions, have at least one genetic factor in common which may well be the autosomal dominant gene responsible for the spike-wave EEG trait. Whether or not the EEG trait is due to an autosomal dominant gene or to quasi-continuous variation would not alter the empirical risk figure reported. On the basis of the former hypothesis, frequency of this major pathological gene is high,  $p = 0.02$ , so that it is carried by approximately 4 percent of a randomly mating population. Its presence may be demonstrated in the resting record or elicited with hyperventilation or intermittent photic stimulation. But whether or not it can be demonstrated depends in great part on the age of the individual at the time the EEG is taken. Thus, in the population as a whole, when all age groups are included, the spike-wave EEG trait may not be demonstrable in more than one percent of those tested.

Many investigators representing different disciplines have suggested, in the last few years, the need for a complete reevaluation of our concepts of epilepsy. In the words of Niedermeyer [19], "Decades of heated discussions have taught us that no straight line can be drawn between the focal, presumably acquired type and the generalized, presumably predispositional type of convulsive disorder." Ajmone-Marsan [1] and Gloor [7] have expressed this same view in different ways. Rodin [22], Bray [3, 4],

Hughes [10], and several others have produced data, in the last two years, in support of genetic factors in the so-called *focal epilepsies*.

Gloor [7], in a most recent provocative review of pathophysiological bases of generalized bilaterally synchronous spike-wave discharge, proposes that this type of generalized seizure is the result of an abnormal interaction of both cortical and subcortical grey matter; for this reason he suggests using the term "generalized cortico-reticular epilepsies" when describing epilepsies characterized by this specific type of electroencephalogram. (For the moment, we shall resist the temptation to adopt the new terminology.)

#### SUMMARY

In terms of recent developments in molecular biology and particularly in biochemical genetics, the clinical seizure observed in an epileptic is very far removed from the primary product of any gene which may be involved. In the strictest sense, clinical seizure has no ordinal position in a biosynthetic pathway, not even as an end product. This also applies to cerebral dysrhythmias recorded in the electroencephalogram. Important as electroencephalography is in studying convulsive disorders, it has no role in the biochemical identification of disease. It would be as if an electrocardiogram were taken in order to ascertain the blood group of the patient. However, both clinical seizure and cerebral dysrhythmia may well be the neurophysiological consequence of a genetically controlled biosynthetic pathway. In this context, it would have to be admitted that knowledge of genetic factors in the epilepsies is still negligible.

Such knowledge may remain negligible, it is feared, unless the neurophysiologist, the neurobiochemist, the neuropharmacologist, the neurobiophysicist—in short, the contributors to and readers of this volume—aid the geneticist and enter the exciting and rewarding field of biochemical genetics referred to by McKhann, Shooter, and Tower. Because this era is one of molecular biology, there is little if any doubt that the breakthrough in epilepsy, when it

comes, will be in the discipline of biochemical genetics. It is surmised that the answer

will probably be, to our surprise and delight, a relatively simple one.

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Dr. TOWER. The best figures come from Montreal. Drs. Metrakos, husband and wife team, who studied this very extensively, have identified a significant percentage of patients in their study who show hereditary tendency toward this. I think the situation here is a little more complex than just saying simply it is inherited.

There may be a predisposition upon which other factors can play and make it more evident in this particular group of patients than others. However, we know that the majority of patients acquire their epilepsy as a result of injuries at the time of birth, injuries later on, head injuries of various sorts in sports, automobile accidents, and so on.

It can also be caused by infection, febrile convulsion, meningitis. It can be caused by tumors and a whole host of things.

Mr. CARTER. Even arteriosclerosis in our elderly may cause it.

Dr. TOWER. Yes, sir.

Mr. CARTER. I have seen some of these particular people who, when they get older and arteriosclerotic and consume a little of the spirits of the fruit of the vine, have convulsions as a result of it.

Dr. TOWER. That is correct, yes, sir.

Mr. CARTER. We have had for many years various treatments for epilepsy, have we not?

Dr. TOWER. Yes, sir, that is correct.

Mr. CARTER. And the treatment has been widespread throughout our country. All physicians, I would say, certainly are taught the treatments and the different medicines which are used, although these have not been completely effective. We do have cases of epilepsy, do we not, many of which are uncontrolled?

Dr. TOWER. Yes, sir, we do.

Mr. CARTER. I believe one theory that I read not too long ago stated that man is unable to discharge through a scarred area of the brain all of the sensations it receives. These are stored up until they attempt to go over the bridge all at once. When they are discharged suddenly in this way, the result is a convulsion. Have you read of that theory?

Dr. TOWER. I am not completely familiar with that, sir. Actually most of the evidence indicates that the problem is an instability in the normal maintenance of the nerve cells in an involved area, so that they discharge more readily and more spontaneously. In other words, the normal control over the discharge of neurons as required is lost. This can arise from a variety of circumstances.

Mr. CARTER. Normally the discharge takes place all the time. We receive certain sensations and they are discharged, but as I have been taught and have read, these sensations are stored over a long period of time because they cannot be discharged due to scarring of the pathway over which they would normally go, but even then they are built up—the neurons build up until they finally attempt to bridge the gap and result in stimulation of all the nerves of the body and cause a convulsion.

But anyway it is a very serious disease. We realize that. Do you think that perhaps in the use of the medicines that we have today we have not been getting sufficiently high blood levels? Is that correct?

Dr. TOWER. This is a very important aspect of the problem. As I think you are aware, sir, recent methods available for following the blood levels in patients have resulted in a significant increase in our

ability to manage these patients by correlating the blood levels with the control of the seizures. For some of the drugs this has increased the efficiency of the drug by a significant percentage by following the blood levels and making sure they are adequate.

Mr. CARTER. And being able to determine the blood levels and to increase them to maximum effective level?

Dr. TOWER. Yes, sir.

Mr. CARTER. What are some of the drugs used now in the treatment of epilepsy?

Dr. TOWER. Of course, the two standbys, which you are familiar with are Phenobarbital and Dilantin, but we have introduced a number of new ones over the past years and I think the new one, Carbamazepine, which has just been introduced this year, and primidone, ethosuccimide, and some of the others have been very useful additions and welcome to the epileptic patients everywhere.

Mr. CARTER. Which one of these causes enlargement of the gingiva?

Dr. TOWER. Dilantin.

Mr. CARTER. How much do you spend for research in the National Institute of Neurological Diseases and Stroke on this particular area of concern?

Dr. TOWER. Our figure for 1973 was \$5.6 million. It went up to about \$6.5 million last year and will remain approximately that figure as we estimate for the present fiscal year.

Mr. CARTER. I believe it was \$6.4 million, as I read it, for research.

Dr. TOWER. That is correct.

Mr. CARTER. How do you disseminate the results of your research?

Dr. TOWER. It is disseminated in several ways. The reports by the investigators in scientific and medical journals; we have a series of monographs that we developed in our Epilepsy Advisory Committee on the present state of the art reports; and the Institute puts out monographs and short bulletins.

Mr. CARTER. How effective has surgical treatment of epilepsy been?

Dr. TOWER. In those cases that are considered suitable for surgery, the figures are somewhere around 50 to 60 percent. We are in the process now of developing a monograph on the surgical treatment of epilepsy which will gather together all the data we have. When that is together, we can give you a more accurate figure than we have now.

Mr. CARTER. What are the methods of surgical treatment?

Dr. TOWER. This is excision of the focus.

Mr. CARTER. Of the scarred area of the brain?

Dr. TOWER. Yes, sir.

Mr. CARTER. Did you every do a prefrontal lobotomy?

Dr. TOWER. No, sir. It will be done in the area identified as a discharged focus. A great many of these are in the temporal lobe.

Mr. CARTER. Thank you very kindly, Mr. Chairman.

Mr. KYROS. Thank you, Dr. Carter.

Mr. HASTINGS.

Mr. HASTINGS. Thank you, Mr. Chairman.

First, I want to commend you, Mr. Kyros, for your great interest here. I would like to say the National Epilepsy Foundation has a great friend in Mr. Kyros. His perserverance and persistence particularly with members of this committee to provide further recognition of this problem has been great, I might say.

What is the incidence of the increase or decrease in epilepsy in the last 10 years, Dr. Tower?

Dr. TOWER. The data are rather imperfect. Our estimate is that we may be adding something in the order of 100,000 a year. How this compares with the attrition at the other end I don't think we know yet. This is an area where we need better figures than we have available to use.

Mr. HASTINGS. We just do not have the numbers to provide a valid judgment in that area?

Dr. TOWER. That's right.

Mr. HASTINGS. I would hope that would be accomplished. That would be a great help to Congress in determining in which direction we should go. Is it an increasing or decreasing problem?

Dr. BERNSTEIN. As time goes on and mechanisms for identification of the problems become better, there are recognitions and diagnoses that would not have been made 10 or 20 years ago. There is an inherent difference in knowing for sure of the change in the process over a prolonged period of time.

Mr. HASTINGS. I am interested in your statement where you say the clinical application of research findings has not kept pace with research and development in epilepsy.

Dr. BERNSTEIN. Perhaps I could just use the example Dr. Tower referred to of a new method for measuring blood levels and the various drugs used in treatment. These measurements use a very complicated sophisticated technique which has been developed in major centers. It will take some time before that kind of a complicated measurement procedure diffuses out so it is available to all the health care practitioners throughout the country.

Insofar as the ability to make the best judgments as to dosage in individual patients may be related to that kind of measurement, then that lack in itself is an index of the failure to diffuse rapidly a technique which could be useful. It is just a natural and ever-present problem.

Mr. HASTINGS. That was my next question. That is a formal lag with this type of technological advancement?

Dr. BERNSTEIN. I believe that would be correct.

Mr. HASTINGS. It is not just a communications gap or lack of financial resources?

Dr. BERNSTEIN. I think those two relate. Certainly the 11 centers Dr. Tower referred to in which feasibility is going to be looked at for an overall and whole approach to the epileptic population will have to include that kind of thing as well.

Dr. TOWER. I would like to augment that statement by saying we feel that information both to the general practitioner and the community and to the paramedical personnel in the area served by such a center would be a major activity and would deal with the problem that you have just identified.

Mr. HASTINGS. Your general position though—and I think this probably is true in almost all the areas of special diseases—is that we should not start creating special commissions, committees, institutes for every disease that is known to mankind. I think that is generally the feeling of HEW.

Dr. BERNSTEIN. Yes, sir. I think the emphasis of the health agency has been to attempt to integrate, to go toward a comprehensive approach to some of the medical problems that we are addressing. And the fact that one is trying to take a more general and comprehensive approach does not necessarily indicate that there is an absence of appreciation of categorical diseases and emphases.

I think functionally what we are proposing to do is generate the kind of information that is proposed in this bill and to do it within the framework of existing HEW capabilities and staff activities using outside advice. It would have the advantage of coming with that of the operating arms of the agencies to transition from new information and advice to actual accomplishments.

Mr. HASTINGS. Thank you.

I might say whether this legislation becomes law in this session of Congress or not, I think obviously the accent that will be placed certainly by the Congress—and I am sure of the suggestion for the national conference—is going to at least put a greater spotlight on the problem of epilepsy.

I appreciate your testimony and certainly under Mr. Kyros' stewardship this legislation is going to receive very careful scrutiny. Thank you very much.

Mr. KYROS. Thank you very much, Mr. Hastings.

Dr. Bernstein, is epilepsy a reportable disease, that is, to the Center for Disease Control?

Dr. BERNSTEIN. I do not believe it is.

Mr. KYROS. Should it be?

Dr. TOWER. Mr. Kyros, that is a kind of a double-edged problem. It would be nice to have it reportable from the sense that we would know how many cases there were, but until all the legislative and social barriers are removed for the epileptic that would pose a threat to many patients in many parts of the country, this cannot be.

Mr. KYROS. That is understandable. Are we looking into the possibility of whether it is going to be reported or not? I am confused by the number of people afflicted. While this is not something that I feel you should be able to come up with totally accurately, there does seem to be too great a disparity between 2 and 4 million on an affliction like this that you have said you have been studying and spending money on.

The latest issue of Research Profiles, published by the National Institutes of Health, puts the figure at 2 to 4 million, yet Health, Education, and Welfare's Public Service Bulletin, issue 1427, puts the figure at 4 million. To me, this disparity of 2 million people afflicted with epilepsy—that should be a great concern to someone.

Dr. TOWER. These figures are derived—the lower figure of 2 million is derived from a number of studies, which have been done on limited samples of population, not only in this country, but in other countries of the world, since epilepsy is pretty much a worldwide phenomenon. It has no geographical boundaries, and these figures are all fairly close to each other in providing a figure of approximately one-half to 1 percent of the population which accounts for the 2 million figure in this country.

However, because many cases are concealed for one reason or another, there is an estimate, and the 4 million figure comes from the

Epilepsy Foundation of America in their recent survey of the cost of epilepsies, that the figures may be double the 2 million which we have been able to identify.

Mr. KYROS. In any event, we could probably do a better job if we turned our attention to finding that estimate; is it true, as your statement says, that most patients enjoy relative freedom from seizures? Is that so, and what are the figures?

Dr. BERNSTEIN. In the sense that Dr. Tower indicated 60 percent of the patients have complete control and another 40 percent have partial control.

Mr. KYROS. I heard the exchange that you had with Chairman Rogers, the discussion about possibly having a national commission that goes out of existence at the end of a year, after giving a report or using this cumulative conference system, which is the normal way to operate that you have had in the past. In what possible ways would the conference that you now recommend be more efficient or less expensive than using a commission forum as under this bill, to study this problem?

Dr. BERNSTEIN. I think our view is that the ability to accomplish the ends that you are interested in resides within HEW as is, and the Assistant Secretary has indicated that he will facilitate progress along the line that you desire. And for administrative purposes, I believe, it would be preferable not to have a statutory commission.

Mr. KYROS. Actually, on the National Commission itself, who would be appointed? Who would it be appointed by? Did you look at the bill on page 2?

Dr. BERNSTEIN. Yes, sir.

Mr. KYROS. Who would the National Commission be appointed by?

Dr. BERNSTEIN. By the Secretary.

Mr. KYROS. Of course, you have absolute control you have great interest by Members of the Congress. We are willing to put up—this might cost \$75, \$100, maybe \$200,000. You would get the money without worrying about it, and you could go ahead, so, actually, it is only a matter of a form and style of going ahead—the objectives are the same.

Dr. BERNSTEIN. I believe the difference is style and approach.

Mr. KYROS. So, it seems to me the most appropriate body to determine that is the legislative body and not you people, with all the respect we have for you.

Dr. BERNSTEIN. We respectfully suggested our position, sir.

Mr. KYROS. I do not have any further questions.

Are there any further questions by members of the committee?

I want to thank you, Dr. Bernstein and Dr. Tower and your associates, for coming this morning. We appreciate your testimony.

As the day progresses, I think we will want to explore whether a coordination of your activities with all of the other many diverse, interested groups and disciplines can be achieved. Is the total effort adequate? Is it working together? And does it have a national focus and direction?

Our next witness may be helpful in answering these questions. He is Mr. Paul E. Funk, chief executive officer of the Epilepsy Foundation

of America, which was formed about 6 years ago through the merger of groups which had been developing across the country for many years.

EFA is the largest national epilepsy organization, and it has been a resource for the many segments of the American public which have an interest in this disorder. EFA is a volunteer health organization, and Mr. Funk served this field for many years in a voluntary capacity. Four years ago, he decided to devote full time to this fine work and, as executive vice-president of EFA, he will outline for us, today, the views of that organization.

With Mr. Funk, testifying for the EFA, are Dr. David Daly and Mrs. Ellen R. Grass.

Dr. Daly is a neurologist with an international reputation. He holds both an M.D. and Ph. D. degree from the University of Minnesota and is president of the International League Against Epilepsy, a worldwide professional group. He currently is a professor in the Department of Neurology, University of Texas Southwestern Medical School at Dallas, and has worked with both the Mayo Clinic and the Barrow Neurological Institute in Phoenix, Ariz. He also holds positions of leadership with numerous professional and governmental agencies concerned with epilepsy and the neurological sciences and has published extensively on these subjects.

Mrs. Grass is presently president of the International Bureau of Epilepsy, a former member of the National Advisory Commission on Multiple Sclerosis and a former member of the National Institute of Neurological Disease and Stroke Advisory Council. But, despite the prestige and honor of these titles and positions, I understand that Mrs. Grass has personally counseled and advised literally thousands of people with epilepsy and their families. She brings more than 25 years of this kind of experience to us today.

I welcome the panel to the committee.

Mr. Funk, welcome to the committee. You may proceed, sir.

#### **STATEMENTS OF A PANEL REPRESENTING THE EPILEPSY FOUNDATION OF AMERICA:**

**PAUL E. FUNK, EXECUTIVE VICE PRESIDENT, EPILEPSY FOUNDATION OF AMERICA;**

**ELLEN R. GRASS, PRESIDENT, INTERNATIONAL BUREAU FOR EPILEPSY; AND**

**DAVID D. DALY, M.D., Ph. D., PRESIDENT, INTERNATIONAL LEAGUE AGAINST EPILEPSY**

Mr. FUNK. Thank you.

Mr. Chairman and members of the committee, I come here this morning to speak for people with epilepsy, who do not believe that we are making enough progress and fast enough, to speak for the families and friends close to them, for the people who encounter and must take care of them in a wide variety of everyday situations and, indeed, for all of us. For anyone may incur epilepsy at any time during his life.

Everyone in this chamber may be confronted with the problem, and

when they least expect it. And everyone in the Nation—in one way or another—shares the problem, for the cost of the epilepsies to the Nation currently stands at a staggering \$4.3 billion a year.

I am pleased, indeed, to be here. For the distinguished members of your committee have played such a vital role in beginning the conquest of so many major national health problems. The country owes a deep debt of gratitude to your chairman, Representative Paul G. Rogers, for his leadership in the enactment of legislation dealing with health manpower training, cancer, drug abuse, heart, blood vessel and lung, alcoholism prevention, multiple sclerosis, and the developmental disabilities.

The members of our organization still vividly remember his comments when he addressed our National Chapters Workshop meeting here in Washington in October of 1970, and have asked that I convey to him today their continuing high regard for his many contributions to the wellbeing of our citizenry.

I congratulate and commend, you, Mr. Kyros, for the electrifying hope which has spread across the Nation as a result of your introduction of H.R. 13405 and your speech to the Epilepsy Society of Massachusetts on May 23 in Boston.

If it would not embarrass you, Mr. Kyros, I would like to suggest including portions of that speech in the record of these hearings.

Mr. KYROS. Without objection it will be placed in the record following your statement [see p. 42].

Mr. FUNK. The foundation is deeply grateful to your colleagues on this committee, who have always been extremely helpful to us in many ways over the years as we go about the task of interpreting the person with epilepsy—and his needs—to the society in which he lives.

I will highlight my statement, which covers essentially seven points. First, I have tried to describe the massive size of the task we are discussing. The national "establishment" concerned with the epilepsies is a large and complex one, including a large number of the Nation's 7,100 hospitals, 400 neurological clinics, 115 medical schools, 6 special centers and other hospitals of the Veterans Administration, a large number of some 3,000 rehabilitation facilities, 1,200 sheltered workshops, 600 special educational facilities, at least 24,000 social workers and psychologists, over 1 million teachers and a large number of the Nation's 345,000 physicians and 700,000 nurses. Particularly important are the 3,300 neurologists, 2,700 neurosurgeons, thousands of pediatricians and many other professionals specializing in the epilepsies; airline cabin crews, fire departments, police departments and many other groups. There are well over 100 voluntary organizations involved, in one way or another, with the problems of people with epilepsy, and at least 30 agencies of the Federal Government—as well as all State governments—are, or should be, involved with the problem in a major way.

If any problem ever cried out for coordination, for organization and for a systematic approach to finding solutions, this is surely it.

Second, I have attempted to describe and position the voluntary organizations to make clear what they have done, what they can do and what they cannot hope to do by themselves to ameliorate the problems of epilepsy.

Third, I have highlighted the legislative milestones over the past 30 years in an effort to indicate where progress has been made, but where further progress is now called for in coping with the disorder many have called "the least understood and the most neglected of all."

I have here a copy of a publication from HEW called "A Common Thread of Service, a Historical Guide to HEW." It tells a story we can all take pride in as to efforts on behalf of the Nation's health. But it does not contain anywhere in it the word "epilepsy."

Next, my statement addresses itself to the Department of Health, Education, and Welfare, the many fine, dedicated professionals there and the many linkages which must exist between HEW, the medical and other professions and the voluntary sector, in order to do more for people with epilepsy:

Despite all that is being done, or all that is to come, there is still a desperate need for some one central coordinating agency, or focal point within government to mesh and to periodically review a coherent program.

The fifth section deals with the problems encountered by people with epilepsy and the parents of children with epilepsy as voiced by them in surveys, and it identified their principal concerns in getting a job, in holding a job, in obtaining insurance, in obtaining drivers licenses, in controlling seizures and building self-confidence and in coping with public attitudes of stigma and discrimination.

Also included are consumer views on legislation, including increased medical research funding, elimination of discriminatory hiring practices, federally funded national health insurance and public education.

My sixth point summarizes current needs in medical diagnostic and treatment areas, social and rehabilitation areas and public information and education areas.

We will be hearing, during the day, from a panel of consumers, a panel of medical men and other panels, which will develop these needs in detail.

Finally, I have suggested some criteria for a national plan, which by its very nature, becomes a statement of national policy, for if we spend certain sums of money at the right time and in the right way, we may be able to make considerable savings in the \$4.3 billion the epilepsies now cost the Nation.

The plan should be designed primarily for execution at State and local levels, and it should command the support of the person with epilepsy himself.

In closing, I would say, let us all regard ourselves as epileptics, for, until everyone does, indeed, understand that we are all potential epileptics, that epilepsy can, indeed, touch the life of anyone at any time, our task is not done. Americans can do much more to end the suffering, the inhumanity, the waste and the indignity of epilepsy.

Everyone must be alerted to his own stake in this fight by bringing the disorder out into the light with a congressional mandate and with a national plan.

It has been an honor, Mr. Kyros, to appear before this committee, and I am deeply grateful for the opportunity.

If there is any further information I can provide, I would be most pleased to respond to your questions, either now, or after the other members of the panel have given their testimony.

[Testimony resumes on p. 44.]

[Mr. Funk's prepared statement follows:]

STATEMENT OF PAUL E. FUNK, EXECUTIVE VICE PRESIDENT, EPILEPSY FOUNDATION  
OF AMERICA

Mr. Chairman and members of the committee, my name is Paul E. Funk. I come here this morning to speak for people with epilepsy; for the people's families and friends close to them; for the people who encounter and must take care of them in a wide variety of commonplace daily situations . . . and, indeed, for all of us.

For *anyone* may incur epilepsy at anytime during his life. Everyone in this Chamber may be confronted with the problem and when they least expect. And everyone in the Nation—in one way or another—shares the problem. For the cost of the epilepsies to the Nation currently stands at a staggering \$4.3 billion a year . . . or over \$20 for every man, woman, and child in the United States. The epilepsies are a *major National health problem*.

My own interest in the problem began some twelve years ago when, as a volunteer, I worked on many public information and education projects. Over the years I began to get more involved and devoted more and more time on these problems until four years ago I decided to devote full time to the epilepsy movement.

So I am pleased, indeed, to be here. For the distinguished members of your Committee have played such a vital role in beginning the conquest of so many major national health problems. The country owes a deep debt of gratitude to your Chairman, Representative Paul G. Rogers, for his leadership in the enactment of legislation dealing with Health Manpower Training, Cancer, Drug Abuse, Heart, Blood Vessel, and Lung, Alcoholism Prevention, Multiple Sclerosis, and the Developmental Disabilities. The members of our organization still vividly remember his comments when he addressed our National Chapters Workshop meeting here in Washington in October of 1970, and have asked that I convey to him today their continuing high regard for his many contributions to the well-being of our citizenry.

I congratulate and commend you, Mr. Kyros, for the electrifying hope which has spread across the nation as a result of your introduction of H.R. 13405 and your speech to the Epilepsy Society of Massachusetts on May 23 in Boston. And the Epilepsy Foundation is deeply grateful to your colleagues on this Committee who have always been extremely helpful to us in many ways over the years as we go about the task of interpreting the person with epilepsy—and his needs—to the society in which he lives.

That task is a massive one and we who are involved with it urgently need help. The Epilepsy Foundation of America is a voluntary nonprofit health organization with some 10,000 members and 164 local chapters across the nation. In all its locations it has a staff of 188 persons, but most of its work is done by unpaid citizen volunteers. Its principal financial support comes from just over one million individual private citizens who contribute an average of \$3.13 each to support the work of the Foundation in Research, Fellowships, Training Programs, Counseling, Vocational Rehabilitation, Governmental Liaison, and, above all, perhaps, Public Information and Education.

Fifty of the nation's top authorities on the medical and social management of the epilepsies—indeed in many instances worldwide authorities—representing 28 medical schools and numerous professional groups serve on the Foundation's National Professional Advisory Board and nearly 1,000 physicians serve on its local Chapter Professional Advisory Boards. The Foundation has close ties with the American Academy of Neurology, American Neurological Association, American EEG Society and the American Epilepsy Society. Liaison representatives from other professional societies, including the American Rehabilitation Counseling Association, National Education Association, and the Child Neurology Society also work with the National Professional Advisory Board. Many representatives of these organizations will be heard here today.

For the national establishment concerned with the epilepsies is a large and complex one. It includes—or should include—a large number of the nation's 7,100 hospitals, 400 neurological clinics, 115 medical schools, 6 special centers and other hospitals of the Veteran's Administration; a large number of some 3,000 rehabilitation facilities, a large number of some 1,200 sheltered workshops,

a large number of some 600 educational facilities, at least 24,000 social workers and psychologists, over one million teachers, a large number of the nation's 345,000 physicians and 723,000 nurses, airline cabin crews, fire departments, police departments and many other groups.

Particularly important are 3,300 neurologists, 2,700 neurosurgeons, thousands of pediatricians, and many other professionals specializing in the epilepsies.

There are well over 100 voluntary organizations involved, in one way or another, with the problems of people with epilepsy, and at least 30 agencies of the federal government—as well as *all* state governments—are, or should be, involved with the problem in a major way.

I cite these statistics in an effort to quickly outline the universe involved and to illuminate the complex and complicated nature of the problem to which all of us must address ourselves.

If any problem ever cried out for coordination, for organization, and for a systematic approach to finding solutions, this is surely it.

The Epilepsy Foundation of America—even were it to grow to ten times its present size—cannot hope to solve the problem alone. It is far too huge. As the Chairman of our Board, the eminent neurologist, Dr. A. B. Baker, of the University of Minnesota, has said:

"In a way, a voluntary such as EFA is performing a holding operation, helping the family, comforting the patient, while medical science tries to find the answers. And while our seed grants on the frontiers of research have value, that search for the answer, if it is to be meaningful, must be largely government financed. Only government has the resources which are needed."

Our own organization has limited resources, has great difficulty in raising funds—at low cost—for what until now has been a largely unpopular cause and, in all candor, is struggling valiantly against inflation, and other pressures to maintain its very existence as national advocate, ombudsman, defender and comforter for the 4-million Americans who have epilepsy.

I pledge to you that our organization will do everything in its power to uphold and vigorously pursue its responsibilities. But our position is a difficult and precarious one, and I can make no forecasts or promises. The job is too big for us alone. The resources of the entire nation must be mobilized.

Above all else, we see our role as being the repository for and/or guide to—all information available on the epilepsies. All of the information presently available mandates, so it seems to us, the development of a national commitment to cope with the age-old enemy of mankind—the epilepsies.

That commitment cannot be the commitment solely of a voluntary health organization; it must represent the best thinking of all segments of our society. And it must recognize that most of the problems posed by the epilepsies will ultimately be solved only by local actions and local programs in local communities. But a National Plan to *guide* those activities is urgently needed.

The concept of a National Plan is not a new one. The National Plan for Mental Health was developed by a Joint Commission on Mental Illness and Health in the late 50's. There is a National Action Plan to combat Mental Retardation which developed from the President's Panel on Mental Retardation in 1962. Thanks to members of this Committee, there is a National Cancer Plan. There is a National Heart, Blood Vessel and Lung program—completed in May 1973. There is a brand new Multiple Sclerosis study. But there is not yet a National Plan for coping with the epilepsies.

There have been many efforts made to generate interest in such a Plan. In 1945, for example, Dr. William Lennox, of Boston, who most people regard as the "father" of the epilepsy movement in the United States, appeared before the House Subcommittee on Aid to the Physically Handicapped of the Committee on Labor and his eloquent words still apply today:

"Of all the handicaps which you and your Committee are studying, epilepsy without doubt is the least understood by the medical and general public and is the most neglected. Like the lepers of ancient times, epileptics still 'dwell without the city' of public understanding and philanthropy."

In 1949, the indefatigable Dr. Lennox was back again and gave testimony in connection with the National Epilepsy Act in hearings before the Subcommittee on Health of the Committee on Labor and Public Welfare of the United States Senate and on that occasion he said:

"\* \* \* so much depends on public opinion and pressure. Now it is all for polio, cancer, and heart disease, all of them important, but all of those things are

obvious. Epilepsy is not obvious. It has been neglected. It needs a place in the sun."

Up until now, perhaps, the closest the country has ever come to an official endorsement for a coordinated effort for epilepsy was back in 1963, when under the auspices of the then Secretary of Health, Education and Welfare, Anthony J. Celebrezze, a Secretary's Meeting on Epilepsy was held. Out of that meeting came a report, which outlined as its purpose:

*"To identify gaps in knowledge, major policies, problems and barriers, at local, State and national levels, which impeded progress is needed research, service, and professional training aspects of epilepsy in relation to health, education and welfare including: clinical and therapeutic, basic research, socio-psychological, community organization, rehabilitation, employment, economic, educational and legal."*

*"To suggest possible courses of action at the national level which would help overcome barriers to progress in prevention and control of epilepsy."*

The Secretary went on to say:

*"All of us here are proud of the progress that is being made against epilepsy. All of us are impatient that that progress be accelerated. I know that you are impatient for more knowledge, impatient that the knowledge we now possess by more widely and more effectively applied."*

But there it stopped until your own Committee in 1970 developed and passed Public Law 91-517, the Developmental Disabilities Services and Construction Act amendments of 1970, which, so far as I know, was the first piece of federal legislation to ever contain the word "epilepsy." This was a landmark piece of legislation. But, I believe—and I am certain that others will so testify—that this was only a beginning. More, much more is still needed.

Earlier in that year, in August, as the volunteer President of the Foundation, I joined with the Presidents of the American Academy of Neurology, the American Epilepsy Association, the American Neurological Association and the International Bureau for Epilepsy in writing President Nixon, as follows:

*"That epilepsy is a serious national health problem can no longer be doubted. Estimates of its prevalence have ranged from a low of just under two million to a high of six million. Using the low figures as a basis for comparison, there are more Americans suffering from convulsive disorders today than the combined totals of those with cancer, muscular dystrophy, tuberculosis, and cerebral palsy."*

*"Among even those epileptics who have attained complete control over their seizures and who are ready and able to work, the unemployment rate is six times higher than the national average, according to the United States Department of Labor. That is considerably higher than the unemployment rate among ex-convicts, and many times higher than among inner-city Negroes and other disadvantaged minority groups."*

*"But that unhappy statistic applies only to those fortunate epileptics who no longer have seizures. How much sadder is the plight of the nearly one million (again, using the conservative estimate as a basis) who can never hope to live without fear of having seizures. Although epilepsy affects persons of all ages, the majority are children and young adults who because of medical traditions and social attitudes may never realize their full potential as productive citizens."*

*"Ironically, at a time when the most sophisticated medical techniques and discoveries can be brought to bear against many of mankind's other ailments, the average epilepsy patient must be content with medications that are effective in controlling little more than one-half of those who suffer from epilepsy. Clearly we need a renewed emphasis on research and training in neurological disorders—the essential basis for continued advances in this field."*

*"Against this gloomy background, we wish to report to you the steps we, the voluntary agencies and professional societies, are taking to attack the public and professional apathy which stifles progress for the epileptic. After years of fragmentation of effort, the numerous small groups working independently in this field have now joined forces for a unified, concerted drive."*

*"Starting from almost nothing, the Epilepsy Foundation of America, which represents the amalgamation of over 30 previously independent agencies, is now realizing over two million dollars a year from a limited fund-raising campaign. This income is being rapidly expanded. Funds are being used for public and professional education, for the development of services, and especially for the vocational and social rehabilitation of the epileptic. There are solid data to demonstrate that the work potential of the epileptic is not being effectively uti-*

lized. Our data show that only two percent of those serviced by our rehabilitation agencies are epileptics."

"For our rapidly evolving program to be effective, however, it must be complementary to that of the Federal Government. We purpose a real partnership, but in our efforts to relate to the Federal program we are frustrated by the lack of any central coordinating agency or focal point within the government with whom we can plan a coherent or coordinated program."

"There is a *desperate need for comprehensive planning*—both within and outside of government—for the epileptic. *We are writing to urge you to establish within the government some individual or committee—some focal point for the review of the national program for the epileptic.*<sup>1</sup> We would like to work with this individual or committee in the development of a *blueprint for action* so that as funds become available to us and to the government, we can move forward according to an efficient and methodical plan."

"Your Administration has emphasized its desire to cooperate closely with the private sector. We feel sure you will agree that the time has now come for both the Federal Government and the professional and voluntary organizations to act on this desire."

Under date of October 8, we received a most courteous reply from the then Secretary of Health, Education and Welfare, Elliot Richardson:

"Dear Mr. Funk:

"The President has asked me to respond to the letter of August 21 sent by you and your colleagues concerning epilepsy. He was deeply interested in your comments and was most appreciative of the cooperation which you have offered."

"We do understand your desire to have a focal point through which the private sector can cooperate with the federal government on specific programs. In relation to epilepsy, as you know, the Public Health Service Advisory Committee on the Epilepsies has partially filled this need for the past few years. However, we do see the need for a review of present coordinating committee activities."

"Your suggestion will be helpful to us in our review of the many facets of the government health programs. I appreciate your interest and I assure you I will keep in mind the points you have presented so effectively as I review the recommendations of the various planning groups."

I should also add that in 1972 the Congress appropriated \$3 million for the establishment of Epilepsy Centers. Unfortunately this appropriation was vetoed . . . twice.

In the interim, much has happened and much credit is due to many individuals within HEW and the Executive Branch of Government. I have followed, with interest, testimony from the dedicated professionals at HEW and I would like to compliment them for their succinct statements as to what is being done throughout the Government at this point in time to cope with the epilepsies. It is also appropriate, I believe, to pay tribute to the work being done by the many fine public servants, including Dr. Donald Tower, Dr. J. Kiffin Penry, Dr. James Cereghino, Dr. William Caveness, and many others at the National Institute of Neurological Diseases and Stroke; to Dr. James Garrett, Dr. William Usdane and others at the Social Rehabilitation Services, Mr. Frances X. Lynch and others of the Developmental Disabilities Division and to many other people in various governmental bureaus. As yet, however, there is still no one central focal point—or clearing house—from which to mount an all out attack on the problems of epilepsy confronting parents and patients.

What are these problems?

Each year between 30,000 and 100,000 people with epilepsy, or parents of children with epilepsy write the Foundation for information and to ask for help. They tell us what they don't tell their doctors . . . they tell us what they don't tell their social workers . . . they tell us what they don't tell government officials . . . they even tell us what they don't tell their wives, husbands or children. The Foundation listens carefully . . . and yields to no one its trusteeship on behalf of the person with epilepsy.

Periodically we survey these people and make use of their answers in determining Foundation priorities. The problems encountered remain remarkably the same and their views on needed legislation remain much the same. In a survey

<sup>1</sup> Emphasis added.

conducted in late 1972, here are the answers in response to the question "Do you have, or have you had problems attributable to epilepsy? If so, what are they?"

	Percent
Getting a job.....	42.1
Holding a job.....	33.8
Attending the school of your choice.....	8.8
Obtaining life insurance.....	33.8
Obtaining health and accident insurance.....	30.1
Obtaining automobile insurance.....	15.7
Obtaining a driver's license.....	35.2

In response to the question "What do you feel is the greatest problem you face?" Here are the answers:

	Percent
Driver's license.....	6.8
Financial.....	3.4
Misunderstanding.....	4.7
Employment.....	21.3
Medical problems.....	14.1
Control of seizures.....	8.1
Having a child.....	2.1
Public attitudes.....	11.5
Acceptance and self confidence.....	16.7

In response to the question: "What legislation do you feel would be most beneficial to the person with epilepsy?" The answers were:

	Percent
Driver licensing.....	25.7
Medical research funding.....	59.2
Discriminatory hiring practices.....	51.8
National health insurance program with Federal funding.....	30.7
Schools.....	26.1
Public education.....	38.1

In a similar survey conducted earlier this year, in response to the question "If the Epilepsy Foundation of America were to undertake a *major* national campaign—which *single* issue do you believe we should tackle first?" The response was:

	Percent
Public information and education.....	23.7
Employment discrimination.....	18.4
Diagnosis/treatment.....	16.5
Program for low-cost medication.....	11.7
Research findings.....	10.3
Prevention.....	8.9
Insurance prejudices.....	6.7
Rehabilitation.....	3.6

I am sure that Mrs. Eileen R. Grass and the panel of people with epilepsy who will appear here today will further illuminate the problems and will comment upon how they may be solved.

In *medical, diagnostic and treatment areas*, there is a need for more comprehensive epidemiological studies, more basic research, research to follow up new surgical techniques, research to appraise experimental studies in electrode implantation, cerebral stimulation; to develop standards for clinics, programs to stimulate drug research, the feasibility of pre-school neurological screening, and plans attract—and to train—additional numbers of professionals, programs to update and to bring current the state-of-the-art knowledge to physicians, set standards for drug blood levels.

The minutes of the most recent (June 24) meeting of the Epilepsy Advisory Committee of the National Institutes of Health indicates very real progress in many basic research areas. It also indicates what must be done to encourage new research and to recruit professionals in epilepsy and the kinds of professional education and workshops which must be brought into being, the new books required, and fruitful areas for the development or testing of new drugs. It contains

data on the present Veterans Administration Epilepsy Centers and reflects the very fine work being done in developing the Comprehensive Epilepsy Program feasibility studies which will soon get underway in eleven (11) locations.

Incidentally, much of the work required for the medical parts of a National Plan will exist, in my opinion, upon the completion of these studies. You have, I believe, invited a panel of witnesses to address themselves to these subjects here today.

*In social and rehabilitation areas*, there is a need to educate teachers, to provide classroom materials and to provide special educational facilities for children unable to attend regular classes; to prevent discrimination in employment, to train and rehabilitate persons with epilepsy to educate employers; to make certain that insurance is available to persons with epilepsy with no increased premiums beyond those supported by actuarial tablets, to strive for uniform driver's laws; as I understand it, a panel of witnesses will address themselves to these subjects here today.

*In public health information and education areas* there is a need to acquaint persons with epilepsy on how to live with their disorder, to answer the questions of parents, to inform large numbers of people what to do about an epileptic seizure and how to recognize the manifestations of epilepsy. There is a need to survey and update public attitudes and there is a need to develop feed-back mechanisms to determine changes in behavior. I know that a panel of witnesses will be addressing themselves to these subjects here today.

*In all areas*, there is a need for more information, for correlated information, for plans and for a central clearing house to exchange data and to report upon progress.

But it seems obvious that a National Plan is needed. Why has a National Plan never been developed? By the professional, by government, or by voluntary organizations? If everyone is for a National Plan, what has delayed it?

Well in the first place and as I hope I have already made clear, the problem is a complex one calling for multi-disciplinary and interdisciplinary approaches and an enormous amount of cooperation between the various kinds of organizations. There is still a wide range of professional opinion on several key questions.

I will give you just one example. Back about a year ago, I began a crusade to improve upon the basic literature published by the Foundation and to bring it in line with what I regarded as the latest and most scientifically accurate information on various topics. But for every reference I cited, someone else on the staff was able to cite another reference proving the *opposite*. Finally, we compiled a list of 14 *key questions* about the epilepsies including heredity, intelligence, epileptic personality, incidence and prevalence, and we then systematically went about recording the *range* of professional opinion on these questions.

The result astounded me, and they astounded a great many professionals. The document which we dubbed "Spectrum" had only internal distribution, for we hoped that professional people would be able to arrive at a consensus on the questions. *Unless* they could, securing *public* understanding of the epilepsies would be a most difficult task indeed. That "Consensus" has now been developed and published.

Still another reason, I suspect, is that we have not been ready to do a National Plan up until now. There was too much work which had to be done first. And that brings me to my second point: *the preliminary data-gathering, the probable costs, and the time required to develop a National Plan.*

To do a meaningful Plan, you need *bales* of information. I'm astonished that the National Center for Health Statistics does not have more data. One would think they would. Information which just hasn't existed up until now. Dr. James Cereghino pioneered several studies, taking inventory on a state-by-state basis, of facilities and services. But although Dr. Cereghino showed us the way, only a dozen or so states have been studied as of this date. In 1971, the Foundation itself conducted a "quickie" study, through its regional managers of needs and facilities. This study took in all 160 major metropolitan centers and although the methodologies employed left much to be desired, it *did* yield valuable *planning* information.

More recently, EFA staff *as* conducted a study of "*Emerging Manpower Needs*" in all of the professional and para-professional fields involved in pro-

viding services to persons with the epilepsies. That study, incidentally, shows that we need to train at least 3500 to 4000 people as soon as possible for local, county and state governments and our own evolving system of chapters manned by citizen volunteers.

It has been relatively recently that we have completed and validated a study on the Cost of the Epilepsies to the nation—a study which identifies the principle costs as follows:

Program:	Annual cost for epilepsy
Aid to the permanently and totally disabled-----	\$70,266,690
Aid to the blind -----	420,423
Aid to families with dependent children-----	53,172,876
Vocational rehabilitation -----	9,648,134
Social security disability benefits-----	63,038,880
Crippled children's program-----	4,700,000
Medicaid -----	31,300,000
Medicare -----	125,300,000
Veterans Administration -----	80,430,210
Special education -----	85,610,270
Institutionalization -----	231,649,000
Unemployment wage and hour loss-----	1,720,224,000
Private medical costs-----	1,879,945,000
Research -----	5,895,252
Total -----	4,372,600,735

I will not elaborate upon that study for it has already appeared—in full—in the Congressional Record.

Even more recently we have completed a study on "Behind the Stigma" and have updated "The Legal Rights of the Person with Epilepsy," and a "Directory of Clinic Facilities," and have moved to completion "Basic Statistics on the Epilepsies."

Professionals everywhere are publishing more—and better—material than ever before. So we should soon have readily available to us most of the basic data required to develop a National Plan. What should it contain and who should be involved in its preparation? Obviously, everyone. For a National Plan is a statement of national policy. We, the people, speak. It is clear that there are between 30-60 professional societies and voluntary organizations who should make contributions.

How long will it take and what will it cost? H.R. 13405 answers the first part of that question. The National Commission is called upon to complete its work within one (1) year and it is my opinion that the task can be done within that time frame. As to the cost, I should think that we are talking about a sum of somewhere between \$200,000 and \$300,000.

What are some of the criteria which should be established for the Plan? One of these, I believe, should be: Social accountability or "cost effectiveness," if you will. Put more simply: If we can come up with the right Plan, if we follow it up with the appropriate legislation and if we spend certain additional sums of money at the right time and in the right places and in the right way—how much of the \$4.3 billion a year can we save?

The second criterion is that the Plan be designed for execution at state and local levels. For the problems of the epilepsies will never be solved by governmental officials or a voluntary health organization headquartered in Washington, D.C. These problems, like most of the problems of our society, will be solved only by concerned citizens working together in local communities.

Above all, perhaps, the Plan should command the support of the person with epilepsy. For whatever the reason—and I can think of many—this person has been strangely absent from the fight in his own behalf. Perhaps he has been consumed with his own problems. Perhaps he fears to identify himself. But with a National Statement of Policy, with nationwide encouragement and support, a National Plan will signal that the time has now come for him to step forward.

Mr. Chairman, I would summarize the benefits thusly. Why a National Plan?

1. Because epilepsy is a complex and major National health problem affecting at least four million citizens at an estimated cost of over \$4 billion annually.

2. Its complexity cuts across many agencies and involves a wide variety of social and medical services.

3. The very complexity calls for a coordinated systems approach—just as other multifaceted medical chronic health problems have experienced via federal attention and impetus.

4. An opportunity for the many organizations and experts involved with epilepsy and its wide ranging consequences to develop a unified, coordinated effort.

5. While a great deal of knowledge has been gathered regarding epilepsy, the effectiveness of any new technology and treatment approaches are dissipated due to lack of a unified National thrust.

6. Thousands of new cases of epilepsy are added each year because a systematic approach to prevention of seizure disorders is not being applied with any systematic rationale.

7. A National Plan would bring together the know-how and the support of the entire national community with a single focus to improve the life of the person with epilepsy through improved laws, health care, public information, research rehabilitation and preventative measures.

8. Only a National Plan developed cooperatively will reduce the fragmentation which currently exists in the programs and approaches now being applied Nationally.

In closing, if I were to comment in an over-all way on the job ahead of us, I believe I would summarize it in this way:

*Make us all epileptics.* For until everyone does indeed understand that we are all potentially epileptic, that epilepsy can indeed touch the life of any one at any time, *our task is not done.*

*Only when epilepsy is regarded in the same way that eye glasses or hearing aids or diabetes or arthritis are regarded will we have won the fight. Man's ills are numerous; they are part and parcel of the human condition; they do not warrant stigma, fear or discrimination.*

*I am convinced that Americans can do much more than has ever been attempted before to end the suffering, the inhumanity, the waste and the indignity of epilepsy.* Everyone must be alerted to his own stake in this fight; to do this, we must truly bring the disorder out into the light . . . with a National Plan

It has been an honor, Mr. Kyros, to appear before the Committee today, and I am deeply grateful for the opportunity. If there is any further information I can provide I would be most pleased to respond to your questions.

[Excerpts from Mr. Kyros' speech of May 23, 1974, follow:]

#### REPRESENTATIVE KYROS TALKS ABOUT EPILEPSY AND A NATIONAL PLAN—ESM ANNUAL MEETING

[Rep. Peter Kyros (D-Me.) is a champion of the epilepsy cause and currently author of proposed legislation urging the appointment of a national commission to study the problems of epilepsy and to devise a national plan to combat its effects. Following are excerpts from Rep. Kyros' speech to the Epilepsy Society of Massachusetts Annual Meeting in Boston on May 23.]

For those of us who have been interested in epilepsy and its problems for some time, it has been gratifying to see an increased awareness in, and recognition of, epilepsy as a national health problem, and I am hopeful that the result will be a national commitment to investigate the nature, causes and effects of this disease and establishment of a plan for control of it.

Certainly the problems associated with epilepsy, the lack of adequate care and widespread misunderstanding on the part of the public about this disability, are receiving an ever-increasing amount of attention and expertise.

As many of you know, this past February I introduced a bill to provide for the establishment of a national advisory commission to develop a national plan for control of epilepsy and its consequences. In March, the bill was re-introduced, this time with the co-sponsorship of the full subcommittee on public health and environment, of which I am privileged to be a member in the House of Representatives.

I suppose each of us has his own reasons to be involved with epilepsy—his or her own commitment to find a cure and to better the lives of those afflicted with the disease.

One incident that happened in January left a lasting impression on me. By finding a way to get around a federal ban on Mogodon, my office was able to bring a Maine child's rare form of epilepsy under miraculous control.

For 18 months the child's family had been giving the drug, obtained through a physician in Canada, to their two and one half year old son, Josh. The same drug is not licensed for commercial use in this country.

Faced with a cutoff on their Canadian supply, the family appealed to my office. Immediately we ran into bureaucratic stonewalls at the Food and Drug Administration which has approved the anticonvulsant, Mogodon, only for experimental purposes.

Finally, we made arrangements to have the family doctor designated as a researcher, so the drug could be supplied through FDA-authorized channels.

Needless to say, the parents were very much relieved by what we could do. Young Josh, they said, was having as many as 70 seizures every eight hours until their neurologist at Montreal Children's Hospital prescribed Mogodon.

After the drug was prescribed, the seizures dropped to nearly zero. Before this treatment, the child could not see. Now he does. He has turned from being a complete vegetable to an active child.

He eats adult food. He runs and plays, and he's just about ready for day care. The doctors say it is a very remarkable case, since most children with this disease—hypsarhythmia—are in institutions.

Being able to assist in this way is very gratifying. But I don't bring the case up merely to compliment my staff—though I am often quite proud of them!

I bring it up to show some of the progress being made in treatment. The treatment of epilepsy has come a long way from those dark days when it received more than its share of the cruelties, failures, and misinformation that preceded modern medicine's coming kicking and screaming into the twentieth century.

Granted—we have grown up from the time we thought the malady the work of demons. We now have some of the facts. We know, for example, that the disability does not result from mental illness, insanity or mental retardation, but, it is still too often that the public associates the symptoms of epilepsy with violent, visible seizures which in truth do not represent the symptoms of all those with epilepsy.

Meanwhile, in addition to treatment, advances have been made in terms of research and prevention. The National Institute of Neurological Diseases and Stroke (NINDS), a branch of the National Institutes of Health under the Department of Health, Education and Welfare, spends some three and a half million dollars annually on epilepsy research. This accounts for the bulk of government study.

NINDS supports five epilepsy research centers throughout the country. Additionally, another million dollars per year is spent on epilepsy research by other government agencies, including the National Institute of Mental Health, the VA, the Social and Rehabilitation Service under HEW, and the Department of Defense.

It is still too often that the cost, public misconception and waste of human potential and degradation of human spirit tax our society with a toll we need not bear, and has a strong responsibility to eradicate.

It is still too often that the delivery of health services in this country resembles fourth class instead of special delivery mail.

It is still too often, finally, that a solvable disease turns into a social disaster.

As long as these problems remain, it is time to give epilepsy the all out national coordination we have given to cancer, heart, alcohol, health manpower and the like—to find a common thread in the crazy quilt of epilepsy care, research, and prevention. Let me describe H.R. 13405. Very briefly, it authorizes the Secretary of Health, Education, and Welfare, after consultation with the advisory council to the National Institute of Neurological Diseases and Stroke, to appoint a national commission to determine the most effective means of finding the cause of and cures and treatments for epilepsy, and to develop a national plan for the control of epilepsy and its consequences. Such study and investigation shall give particular emphasis to the need for additional financial support by the federal

government and the means by which the federal government can best participate in this effort.

The secretary shall appoint to the commission three members of the advisory council and six other individuals who by reason of experience or training in the medical, social, or educational aspects of the epilepsies, are specially qualified to serve on such commission: To include a representative consumer of services to be designated by the Epilepsy Foundation of America, and two representatives of the National Advisory Council on Developmental Disabilities.

The duties of the commission would be to—

(1) Consult with concerned organizations with the purpose of stating the problems and defining the gaps in and barriers to existing health care delivery systems;

(2) Make a comprehensive study of the state of the art of medical and social management of the epilepsies in the United States;

(3) Investigate and make recommendations concerning the proper roles of the federal state governments, and the national and local public and private agencies in research, prevention, identification, treatment, and rehabilitation of persons with epilepsy;

(4) Develop a comprehensive national plan for the control of epilepsy and its consequences based on the most thorough, complete, and accurate data and information available on the disorder; and

(5) Transmit to the secretary for transmittal to the President and the Congress a final report (which shall include recommendations for such legislation as the commission determines is necessary) not later than one year after the date of enactment of the act.

That basically, is a summary of what my bill would do. It would mobilize the vast resources of the Federal Government behind a national plan of action.

With a similar resolution introduced on the Senate side by Senator Dominick from Colorado, I think that we can bring some focus to fragmented federal efforts to deal with the disease, which, as far back as the 1940's was called "the least understood . . . and most neglected" of all.

Mr. KYROS. Thank you very much, Mr. Funk, for a very enlightening and helpful statement.

I think we will take the statements of the other members of the panel and then the committee may inquire.

#### STATEMENT OF ELLEN R. GRASS

Mrs. GRASS. Thank you, sir.

I wish to address the Honorable Paul Rogers, the Honorable Peter Kyros, and the members of this House Subcommittee on Public Health and Environment.

Ladies and gentlemen, the honor of appearing before you is outweighed only by the awesome sense of responsibility I feel in doing so. You will understand my message better if I briefly sketch my background.

As a clue to my background, which Mr. Kyros read, this particular Yankee was trained in neurophysiology, or the science of how the brain works, at Radcliffe and Harvard Medical School, before Harvard officially admitted women. Because I have had the honor to serve both on committees of the NINDS and on the National Commission for Multiple Sclerosis, experience would dictate that my opinion on both services is perhaps relevant at this moment.

My opinion is without doubt that, for epilepsy at this point in time, the Commission approach is the right one.

My interest, however, also lie in the encouragement of fundamental research in the neurosciences as well as the clinical aspects of neuro-

logical disorders and most certainly in the equitable distribution of health care to the neurologically disabled.

May I officially request, sir, that the 12 pages of written testimony submitted become part of the record, and although H.R. 13405 deals with a national plan for the control of epilepsy and its consequences, solutions of the fundamental medical problems are clearly impossible in the absence of basic research in the neurosciences of adequate quality and quantity.

My written testimony contains pertinent statements from the current president of the National Academy of Sciences and excerpts from the reports of the National Advisory Commission on Multiple Sclerosis on this thesis.

Mr. KYROS. Without objection, your entire testimony will be included in the record [see p. 47], and you may proceed to paraphrase it as long as you wish.

Mrs. GRASS. Rather than speak a little bit about a lot of things to be covered later in more detail by the panel, and for lack of time fail to do justice to any of them, and assigned the responsibility as advocate for the several million U.S. citizens with epilepsy, I asked myself before dawn this morning what one message they would all agree on.

Ultimately the answer became quite clear. They would ask that we look into the future. I have received thousands of letters since the mid-1940's that deal with the many specific important concerns that relate to the sociomedical problems of living with epilepsy, and my written testimony contains a complete, very dramatic composite example I urge you to read.

The typical letter usually begins: "Dear Folks: Doc has just told us that our 8-year-old son, Joe, has epilepsy. It has come as a terrible shock, and we do not know what to do."

The questions about treatment, schooling, medicine, blame, guilt, driving licenses, murder, and so forth, follow. Some can literally tear you apart emotionally if you permit, and I could have read you the rest of this letter with very dramatic effect, but it is really not very constructive.

Rather, I would really prefer to deal with the clincher question which frequently appears in such letters—and Joe's family is writing now.

"How can people help from having epilepsy?" These simple people, often rural, usually impoverished and poorly educated, and lacking access to the great institutions of medicine, raise the most important question of this century to which we can address ourselves on their behalf. And we really have not listened nor yet begun to respond.

It is a fundamental axiom, gentlemen, of the discipline of public health that prevention is preferable to treatment. After all, we all know the old saying: "An ounce of prevention is worth a pound of cure." Considered from a strictly economic point of view there are, say, 4 million persons with epilepsy in the United States now, and new cases caused by head injuries alone are being added at the rate of some 200,000 a year.

There simply are not sufficient numbers of trained personnel, health care facilities, nor dollars available to deal with the magnitude of the epilepsy problem in an ideal fashion. The strategy therefore must be first to cope with current problems using existing means at maximum efficiency.

That is, essentially, we should conduct a holding operation while spending our major efforts on prevention of epilepsy and its major consequences.

Is this game plan realistic and achievable? Yes, I believe it is. Can we ever hope to eradicate epilepsy totally? Probably not; but within the 25 years remaining in the 20th century, I believe it is possible to reduce its incidence by some 25 percent and the severity of its consequences by another 20 percent to the benefit of at least 1 million persons. What potential benefactors you can be by support of this legislation.

Now, because I am fundamentally a scientist, I cannot make such a prediction and recommendations without specific for instances that show that the basic knowledge for achievement of this objective is emerging, and I will be quite brief about them.

First, the matter of febrile convulsions. Simply stated, febrile convulsion occurs in infants during an episode of high fever. The incidence is between 1 percent and 3 percent of all children. Of those, roughly 10 percent develop epilepsy permanently and do not out-grow it.

After several decades of diligent work, Dr. Margaret Lennox recently reported the medical circumstances that determine statistically which of these children will later develop full-blown epilepsy and further statistics to prove that a common anticonvulsant, phenobarbital, can administered prophylactically to prevent this from happening.

A few weeks ago—and this is my second “for instance”—I had the pleasure of an audience with Senator Percy of Illinois, who sponsors Senate bill S. 3556, the purpose of which is to provide a uniform motor vehicle speed limit throughout the United States of 55 miles an hour.

What does this have to do with the prevention of epilepsy? As Paul Funk has just said, anyone in this room can become an epileptic by sustaining a head injury as a result of automobile accident. The estimated possible reduction if the speed limit is reduced and if fewer vehicles are on the road is 3,000 fewer cases of posttraumatic epilepsy per month, or a reduction from 160,000 to about 120,000 per year as a consequence.

The written testimony has an error in this respect which I would like respectfully to correct.

Further, there is increasing evidence that it may be possible to prevent development of posttraumatic epilepsy even after a head injury by suitable prophylactic administration of anticonvulsants.

It goes without saying that efforts to promote peace in the world will also have an automatic benefit in reduction of posttraumatic epilepsy due to penetrating projectiles.

Recent research further demonstrates that once a brain area has participated in abnormal seizure activity, its threshold for further seizures is reduced so that the second time around less provocation is

necessary to precipitate the next seizure resulting in a very dangerous progressive state.

This means that recurrent seizures must be prevented. One of the persons testifying earlier told about the improved control of seizure through new methods of serum level analysis. If Joe's overworked and frequently isolated family doctor has had time to read the medical journals and to go to medical meetings recently, he will know about this. Maybe he even knows where to send the samples. But I would put the chances at about 1 in 10,000 at the present time.

If he did know this, however, he would know that seizure control leaps from 47 to 61 percent simply when medicine is taken regularly and in the prescribed amounts.

He can also determine if there is some peculiarity about this particular Joe's body chemistry that would be a cause for dosage adjustment. Ultimately seizure control can be improved by a factor of about 10 to 15 percent by this method of serum level analysis.

Now I have said progress toward prevention is achievable, but I do not think it is achievable without a national plan, a national commission, and the coordinated cooperative willing efforts of the Department of Health, Education, and Welfare, NINDS, the lay society, Epilepsy Foundation of America, the medical professional societies and all the other elements of the epilepsy universe.

The message from the folks back home then, our constituency and yours, is, "Have courage to think into the future." They say, "Deliver us from evil," the evil of epilepsy, for that surely is what epilepsy is. I am sure they would not consider me blasphemous and I hope you won't, when I say the following five words: "For Thine is the power."

Gentleman, you do have the power. Let's use it for the public's health.

Thank you.

[Testimony resumes on p. 52.]

[Mrs. Grass' prepared statement follows:]

STATEMENT OF ELLEN R. GRASS, FORMER MEMBER, NINDS ADVISORY COUNCIL, PRESIDENT, INTERNATIONAL BUREAU FOR EPILEPSY, MEMBER, NATIONAL ADVISORY COUNCIL ON MULTIPLE SCLEROSIS, PRESIDENT, GRASS FOUNDATION

To the honorable Paul G. Rogers, the Honorable Peter M. Kyros and members of the House Subcommittee on Public Health and Environment. Ladies and Gentlemen, the honor of appearing before you is outweighed only by the awesome sense of responsibility I feel in doing so. You'll understand my message better if I briefly sketch my background. I am Mrs. Ellen R. Grass, former member, NINDS Advisory Council; President, International Bureau for Epilepsy; member of the National Advisory Council on Multiple Sclerosis; and President of the Grass Foundation. A Harvard-Radcliffe complex gave me both undergraduate and graduate training in neuro-physiology, ending in the mid-thirties. Ever since then my professional work, my charitable concerns, and my service to the United States Government Health establishment have kept me interested, aware, and busy in the encouragement of fundamental research in the neuro-sciences, in clinical aspects of neurological disorders, and in the distribution of health care to the neurologically disabled public.

You can appreciate why then, I preface my remarks on H. R. 13405, the National Plan for the control of epilepsy and its consequences, with a broader plea that this highly respected committee use its not inconsiderable power to ensure that basic research in the neuro-sciences be nurtured with all the tender loving care and federal greenbacks that you can muster.

Dr. Phillip Handier, president of the National Academy of Science, recently said, "One cannot yet calculate the melting point of a crystal from fundamental considerations, predict the manner in which a protein will fold, specify an exact structure of an enzyme to catalyze a specific process, predict the behavior of a living cell, much less account for the functioning of the central nervous system in more than a trivial superficial manner."

In 1973-74 I had the honor of serving on the National Multiple Sclerosis Commission initiated by one of your number, the Honorable Margaret Heckler.

Multiple Sclerosis is, as you know, also a dreadful neurological disorder. Epilepsy most assuredly needs a commission to render the same kind of thorough result. In the report of the Multiple Sclerosis Commission, a very strong plea is made for support of basic bio-medical research in the neurological sciences, a plea with which I heartily agreed and, indeed, insisted. The Commission recommended that "The small sum of twenty cents per unit of population be spent for the support of promising meritorious bio-medical research in the neurological sciences."<sup>1</sup> Of the recommended research expenditures for the fiscal years of 1975-77, basic research at NINDS exceeded targeted research by a ratio of more than two to one.

I turn now from my role as an advocate of basic research in the neurological sciences to one as an advocate for persons with epilepsy. With continued respect dating back to our common educational experience at Harvard Medical School, I have listened to Dr. Tower tell of the achievements of NINDS in epilepsy. These are not exactly unknown to me because of my four years of service on the Advisory Council to NINDS, a tough, demanding duty to my country which turned out to be perhaps the greatest pleasure of my life.

Neurological diseases account for 20% of the hospitalization in the United States every year, and 12% of the deaths. The neurological and communicative disorders afflict over 40 million Americans at an annual cost to the nation conservatively estimated at 20 billion dollars—not millions, billions. Those figures reflect the chronic, often debilitating course of the disorders and the fact that we still lack much of the basic information to understand what they are, and how to prevent and cure them effectively.

Dr. Donald Tower, Director of NINDS, points out that the human brain has a total of 10 billion neurons, or nerve cells, and an even larger number of supporting cells that comprise a device that is remarkably efficient at managing our lives, and does this within the confines of a unit that weighs less than 4 pounds and expends only 20 watts of power. You recall that a 20 watt electric light bulb doesn't shed very much light.

Now let's focus a bit more sharply on epilepsy itself. In a pamphlet brought out by the Epilepsy Foundation called *Research Into the Epilepsies*, Dr. Tower has said, and I quote him: "If I were asked to pick out one program in which I could support research both basic and clinical, I would pick epilepsy because this is such a broad subject that almost any area of neurological research impinges directly or indirectly on it."

You have also heard from several consumers directly who told you candidly and eloquently what it is all about to have epilepsy. However, bear in mind that they cannot be a fair sample, four persons of four million, and variations of types of seizures, degree of control and degree of handicap are extremely great. There are problem areas in epilepsy that make it different from other disorders. First of all epilepsy is not a disease like measles and mumps. It is the symptom of a nervous system disorder. Just as running a temperature is usually a symptom of an infection, and stomach cramps are frequently the symptom of an upset digestive tract, so epilepsy is the symptom of a problem in the central nervous system. For epilepsy the type of symptom, the fit, or seizure, or whatever you wish to call it, is related to where the central nervous system is misbehaving. The problem may be structural or functional or both.

Another thing about epilepsy is that it is not the same from one person to another. All persons with epilepsy DO NOT fall to the ground, thrash about and fail to respond to questions, although some do. Others have much more subtle changes in their state of awareness. Some people have had only seizures in childhood associated with fever, and others have seizures only at night. A small number of persons have, in addition to their epilepsy problems, problems of

<sup>1</sup> Report and Recommendation, National Advisory Commission on Multiple Sclerosis, vol. 1, p. 53 and vol. 2, pp. 124-129.

learning or mental retardation. Some have bizarre psychiatric symptoms in addition, and some have various types of motor complications.

Here's something else that epilepsy is NOT. It's not a single major crisis which, when surmounted is over and done with like a severe bout of viral pneumonia, for example. If the underlying brain disorder is present, the symptom epilepsy is a "Till death do us part" situation. Medicine simply prevents the vast majority of the seizure symptoms from breaking through and resulting in a convulsion.

Now what about the numbers game in epilepsy? How many people really have it? There is considerable disagreement about this and the major reason is in the understandable reluctance of people to disclose the fact that they have seizures. It's also due to the difficulty in recognizing the minor forms of epilepsy and the problem of deciding whether a single seizure should be included or excluded. In other words, should a single fit label a person epileptic? In addition some people feel that seizures that result from head injuries should not be considered epilepsy. All this difference of opinion makes it very difficult to count heads. An average percentage prevalence of 2% of the population is used, and the present number of persons with epilepsy may be quoted as between 2 and 4 million. Regardless of the number, this is a very large segment of people with problems, and many, many families are involved.

I think it's important to remember that seizures can result from brain injuries sustained in automobile accidents or other head injuries, from biochemical imbalances (particularly in small infants), from infections of the central nervous system, and a host of other causes.

It is, however, primarily a disease which begins in childhood. It is estimated that there are some 670,000 elementary school children with seizures, and an additional 300,000 secondary school children with seizure disorders. If you add that up, it makes nearly a million afflicted children. It is awesome and humbling to try to speak for this multitude.

But if I could use but four words as their message it would be, "Deliver us from Evil." Webster's collegiate dictionary gives us its first definition for deliver, "to set free." There is a great deal of talk these days and properly so on the freedom afforded citizens of the United States by the Constitution. I believe that Americans have the right to expect their Government to take all reasonable and prudent steps to deliver or set them free of the evil of epilepsy. The word "evil" is neither over vehement nor exaggerated. In this presumably enlightened age of increasing social advancement, the evil stigma of epilepsy continues to resist all our efforts to make it go away. People still consciously or unconsciously associate epilepsy with something mysteriously dreadful, like evil spirits, madness, dogs that howl at night and unspeakable terrors and guilt. If we could only achieve the single objective of persuading the public to regard epilepsy as one of the chronic neurological disorders without emotional overtones, our efforts at solving the medical problem itself would be immeasurably facilitated and the distribution of care greatly helped.

I've put together a composite letter out of the incredible number that have been sent to me and to epilepsy society offices over the past years from people with epilepsy and their families, and 48% of these letters come from people in rural areas.

It's my opinion that there are, for each one who does write, an equal number of those who do not. Some of them are too young or too old to write, and some them never learn to write and, perhaps, never will. Many are afraid to write for fear of identification, and others are so discouraged and weary from the way they have been treated by society that they feel writing wouldn't be worth the effort. Many more are cruelly isolated within the largest of our cities, the inner core of our cities, by poverty or language, or for a variety of other reasons, *I'd like to share with you a typical letter.*

It very frequently starts off, "Dear Folks," and it's a very chatty kind of communication.

"Our doctor has just told us that our eight year old son, Joe, has epilepsy. It's come as a terrible shock, and we don't know what to do. What is epilepsy, and why did it happen to us? Is it our fault? What did we do wrong? Is is something that runs in the family? Aunt Josephine used to have spells, although everyone tried not to mention it. Would it be better to keep Joe home from school, because his teacher figures it will be a lot of trouble for them and his

classmates are either afraid of Joe or think he is queer? Lately he doesn't seem to have many friends. Even if he goes to school, will he be able to learn like the others? Friends have told us that epileptics are slow and stupid and can't learn. And then what about a job? It'll be hard for us to support him if he can't work. Who will want to hire him? What will he say when he looks for a job—that he didn't finish school because he has this?

"We go to church regular and try to teach our children always to tell the truth, but if he tells, will he get work? And what if he falls down on the street? People are so very cruel. My husband, Ed, and I worry about his future when we're not around. Joe takes his medicine like the doctor said, and it helps some, but he still has these spells once in a while. So far we've been able to afford the pills, but don't know about next month. Is there any welfare for this? Secretly, can you tell us if it's bad for him to keep taking these pills, drugs you know? Will they make him stupid?

"Doc is so busy we haven't talked about it, but should Joe get married later on and have children of his own? It would be deadful lonely for him if he couldn't have someone to look after him, but who would ever want him? A fit isn't a very nice think to look at.

"But dear lady, the worst nightmare is not knowing about this. We read in the papers and seen on TV how some murders did it because they have something like epilepsy wrong in their heads. Is Joe apt to hurt or even kill somebody when he has one of these spells that he wanders around not knowing what he is doing? He's getting big and strong lately. Must we keep watch on him day and night? And, dear lady, how can people help from having epilepsy?"

It generally concludes by saying, "Thank you for anything you can tell us or send us so we will know better." Once in a while a quarter is scotch-taped to the end of the letter.

The content of these letters hasn't changed much in the last twenty-five years. Once you've learned self discipline enough to swallow the lump in your throat and channel your upsurge of compassion into constructive action, you have to come to grips with the real necessity of how to answer Joe. And we must ask ourselves periodically whether our ability to respond constructively is improving at an appropriate rate.

In response to "What is it?", there are many areas in which we've materially improved basic information about epilepsy and the availability of such information. For this NINDS and EFA deserve our praise. However, there is a very long way to go still in the information and education field. The *School Alert Program* of EFA is a case in point. It furnishes the whole school community with common sense information about epilepsy and is written to foster constructive, realistic attitudes. All the hard work of preparing, producing, and testing the materials is done, there have been several years of experience in distribution, and it has been pronounced excellent by consumers. The problem is that the demand for the materials exceeds our ability to pay for it by a factor of at least ten times.

In response to "What causes it?", most neuro-physiologists postulate that an improper balance of some of the simpler body chemicals (sodium, potassium and perhaps magnesium) exist in that part of the brain which is acting up, and contribute to the abnormal electrical activity of the nervous system that accompanies seizure activity. There is also considerable basis for the belief that improper balance of the more complex body chemicals, the sub-units of proteins called the amino acids either cause or result from such abnormal brain activity.

Recent research demonstrates that once a brain area has participated in such abnormal seizure activity, its threshold is reduced so that less provocation is needed to precipitate the next seizure and this is a dangerously progressive state. The lesson there for the clinician is obvious.

How well is medical therapy succeeding? Can we reassure Joe's family on that score? Well, yes and no. We do indeed know how to treat epilepsy much, much better than we did when Joe's folks wrote first, five years ago, but it isn't necessarily true that the local family doctor will know about these new methods or be equipped to use them to best advantage.

Now take the matter of Joe's pills. If Joe's overworked and frequently isolated family doctor has had time to read the journals and to go to medical meetings, he knows about anticonvulsant blood levels. Maybe he even knows where to send the samples for reliable analysis. I'd put the chances at about one in 10,000 at the present time. If he did know this, however, he would know that seizure control in a group of patients leaps from 47% to 61% when medicine is just

simply taken regularly. He can also determine if there is some peculiarity about Joe's body chemistry that calls for dosage adjustment. As yet, an insufficient number of laboratories in the United States have the capability of making these measurements reliably.

Can epilepsy be prevented? Well, that's a good question. Joe's family asks, "Dear lady, how can people help from having epilepsy?" This rural family, impoverished and poorly educated, lacking access to the great institutions of medicine, has politely phrased the most important question of all, because all the money in the whole HEW budget would not be sufficient to provide maximal desirable services for persons with epilepsy unless we commence a program of prevention. The International Bureau for Epilepsy is an international infant, a poverty stricken one at that, but we do gather ourselves together periodically to face issues, and at the first International meeting in London, we decided to have a symposium on prevention. There were a lot of crepe-hangers ahead of time who said there wouldn't be anything to talk about, but it did provide a great deal of useful information and has resulted in increased awareness that it is no longer necessary to accept that the incidence figures can not be altered, or that the number of intractable cases can not be materially diminished. There are numerous additional approaches possible but I will cite only three that can be numerically verified by recent information.

In a classic work on febrile convulsions published this year, Dr. Margaret Lennox has researched the statistical evidence about this condition, its prevalence, and the probability of its development into clinical epilepsy in the later life of the child. Prophylaxis, the word physicians use for administration of medicine to prevent development of disease, is in these cases definitely indicated for some such children, and its effectiveness, the type of drug, the dosage, etc. have been worked out in exquisite detail. It remains only for the physicians of the world to be informed and to practice accordingly. This may take a great deal of doing.

A few weeks ago I had the pleasure of an audience with Senator Percy of Illinois the sponsor of Senate bill S. 3556, the preface of which is to provide for a uniform motor vehicle speed limit throughout the United States of 55 m.p.h. What has this to do with epilepsy? Anyone in this room can become an epileptic by sustaining a head injury as a result of an automobile accident. Indeed before the energy crisis about 160,000 persons developed seizures each year for this reason. The estimated possible reduction (due both to reduction of speed and fewer vehicles on the road) is 3,000 fewer cases of post traumatic epilepsy per month or about 120,000 fewer per year. The potential saving in personal, family, and social suffering and economic expense is evident to any thinking person.

Further, there is increasing evidence that it may be possible to prevent development of post traumatic epilepsy even after a head injury by suitable prophylactic administration of anti-convulsant medication.

Earlier I spoke of the methods of analyzing how much medicine effectively enters the body fluids of the person with epilepsy and how, by measuring, this medication can be adjusted. Ultimately, seizure control can be improved by a factor of at least 10 to 15 percent by this method. Anyone with a midjet computer can easily figure what the savings to the country would be thereby.

Given only these three preventive elements, the possibilities are challenging. Eradicate epilepsy totally? Probably never—but reduce its incidence by some twenty-five percent and reduce the severity of its consequences by another twenty-five percent within the twentieth century? Yes, it *could* be done but not without a National Plan, a National Commission, and the coordinated efforts of HEW, NINDS, EPA, the professional societies, and other elements of the epilepsy universe. May I emphasize that work on all levels is essential—funding of the basic bio-medical research, participation in clinical research and trials, distribution of effective information and educational materials to physicians about modern techniques of treatment, and an education of the public.

I would like to close with a poem by my favorite poetess, Edna St. Vincent Millay:

"Upon this gifted age, in its dark hour,  
Rains from the sky a meteoric shower of facts.  
They lie unquestioned, uncombined,  
Wisdom enough to teach us of our ill  
Is daily spun, but there exists no loom  
To weave it into fabric."

Mr. KYROS. Thank you, Mrs. Grass, for a very fine statement. The next member of the panel is Dr. David Daly.

Dr. Daly, welcome to the panel.

### STATEMENT OF DR. DAVID DALY

Dr. DALY. Mr. Kyros and members of the committee, I would like to request that my written statement be inserted in the record and in view of the limitations of time, I would like to paraphrase only a few points raised by it.

Mr. KYROS. Without objection it is so ordered [see p. 55].

Dr. DALY. I would suggest that epilepsy often goes too long undiagnosed and indeed epidemiologic studies suggest that in as many as 20 percent of patients an interval of several years may lapse between the onset of seizures and the definitive diagnosis of epilepsy.

There is evidence that seizures themselves are often inadequately treated and accompanying neurological deficits unrecognized. The disruption of the patient's way of life by this chronic disease may lead to severe educational and occupational disability.

I would suggest that the problem is highly complex and I am less sanguine about an easy solution of the many facets to this disorder.

Dr. Bernstein referred to the Secretary's advisory committee. I had the privilege of serving on that committee as the chairman of the Subcommittee on Service and Service Training. The surveys we made on that subcommittee showed a dismayingly widespread lack of coordination between the many agencies involved with epileptic persons and that, as a result of this, patients frequently circulated slowly and fruitlessly among the agencies.

The resolution of this problem is complex and I would submit if a conference could have done it, it should have been held long ago because this was indeed the recommendation of the subcommittee. Unfortunately the subcommittee was abolished by administrative order after a very short term of office and its work and its report went unnoted.

I would suggest we do, indeed, need a comprehensive care program for epilepsy and that this must be much more than simply a better utilization of existing knowledge and facilities. Instead, such a program must be a system which will: provide better health care delivery, recognize and attack the educational and occupational disabilities, and address itself to the as-yet unsolved problem of providing continuity of care for a disease which may well persist throughout the lifetime of the individual.

In addition, a need exists for facilities with advanced techniques in diagnosis and treatment. In my opinion these facilities must have residential capability since the complex of problems which beset the epileptic person do not arise overnight and cannot be solved overnight. In my capacity as president of the International League Against Epilepsy, I have had the opportunity to study the approaches to the problem made throughout the world. Norway has established a National Hospital for Epilepsy. To it come the most difficult patients who may remain for weeks or for months. During this time children attend school within the hospital and adults receive vocational training. Upon the patient's return home the National Hospital maintains contact

through the local physician and stands ready to offer further assistance or rehospitalization as needed. An analogous institution exists in Meeren Bosch in The Netherlands. In Great Britain, as a result of the Reid report, the Government has mandated the establishment of regional epilepsy centers geographically dispersed across the country.

In the United States the Veterans' Administration is establishing a series of regional epilepsy centers. These will have advanced technologies including resources for continuous radio telemetry of the electroencephalogram, video recording for the precise observation of seizure patterns, and gas-liquid chromatography for the accurate determination of serum levels of antiepileptic drugs. Since such capabilities exist in this country, I believe they should be available to all epileptic persons according to their need.

Long-term institutionalization is required for only a small minority of epileptic persons. Earlier in this century many States had special hospitals for epileptic persons needing custodial care. Unfortunately in recent years this trend was reversed, leading to the closure of such institutions and the mingling of epileptic patients with psychotic and retarded patients. On the balance this has led to a deterioration in the care of those persons needing institutionalization solely because of uncontrollable seizures. The proposed commission may very well seek to reverse this trend.

Second, we need much better application of our existing knowledge. There is an insufficient number of people involved in the care of epileptic persons. Many physicians, including neurologists, have relatively little interest in the epileptic patient. We need to improve the teaching about epilepsy to medical students and to residents in pediatrics, internal medicine and neurology. But to do this requires more people highly trained in this complex area.

At the present time it is difficult to find neurologists trained in epilepsy to head the regional epilepsy centers in the Veterans' Administration. We also need many more well-trained people in the allied health sciences, for example, electroencephalographers, EEG technologists, neuropsychologists, public health nurses, social workers, and vocational counselors.

To accomplish this will require the appropriation of funds and the establishment of training programs. This, I would submit, is a matter of the greatest urgency.

We also need to provide opportunities for practicing physicians to update their knowledge and keep abreast of current progress. Gas-liquid chromatography (GLC) provides a means for the rapid and precise determination of blood levels of antiepileptic drugs. Utilization of this technique leads to a marked improvement in seizure control and reduction of dose-related intoxication. Unfortunately many physicians do not know how to utilize the results of GLC determinations. Beyond this, in many communities the procedure is not available and there is also disturbing evidence to suggest that some laboratories are supplying unreliable results. Thus, an urgent need exists to extend the availability of GLC technology and to assure the reliability of the determinations.

The flood of medical publications makes it difficult to keep abreast of knowledge. NINDS wisely recognized this and supported the estab-

lishment of Epilepsy Abstracts which attempts to summarize and categorize publications in the field. This publication has now become self-supporting. In the framework of comprehensive care a need exists for ready access to new information particularly by the advanced care facilities.

NINDS has again led the way by establishing a computerized information search and retrieval system. This system makes possible the automatic search of both title and text in the thousands of epilepsy abstracts. Unfortunately this system is currently shut down because of lack of funds. The proposed commission will surely address itself to the entire problem of availability and dissemination of information and would, I hope, recommend reactivation of the epilepsy information system—epilepsy abstract relief system or EARS.

Finally, in the area of basic research, fundamental questions about epilepsy remain unanswered. This year, for the first time in 14 years, a new antiepileptic drug, carbamazepine, will be introduced in the United States. We need to accelerate drug development and we need to know much more about how antiepileptic drugs work. Clinical testing of new drugs has often lagged because of the difficulty in obtaining carefully studied groups of patients on whom to try new drugs. Implementation of the comprehensive care program would do much to alleviate this problem.

A need exists for systematic screening of potential antiepileptic drugs and this, in turn, suggests a need for a better understanding of their mechanisms of action. In turn, we need a deeper understanding of what makes nerve cells epileptic. Many of the experimental models of epilepsy involve physical or chemical injury to the brain, for example, the freeze focus or the alumina-cream focus.

A more recent technique of electrical stimulation called kindling offers a new direction. In experimental animals kindling seems to be prevented by the administration of some antiepileptic drugs, but not by others. Clearly here is an important clue to the mechanism of action of drugs.

Paradoxically, we cannot answer the seemingly simple question: how many persons have epilepsy? Using available data, one can project from 1 to 4 million persons in the United States. In general the more recent and more carefully conducted epidemiologic studies yield higher prevalence figures. However, to answer our question reliably requires far more extensive studies. The results of such studies would do much to define one of the dimensions of our problem.

Let me conclude by saying that epileptic persons constitute a silent and often hidden constituency. The actions of the Congress over the past 30 years express a recognition of their needs. However, this constituency itself has often not made vocal the full extent of its needs. This we are attempting to do today in the hope that the establishment of a national commission will lead to a focusing of our resources and capabilities. Compelling humanitarian reasons exist for our doing this. But, in addition, restoring epileptic persons to a useful existence will, by making them contributing members of our society, economically repay itself many times. To paraphrase Winston Churchill, in few diseases will so small an investment do so much for so many.

Thank you, Mr. Chairman, for this opportunity to appear before the committee.

[Dr. Daly's prepared statement follows:]

STATEMENT OF DAVID D. DALY, M.D., PH. D., PRESIDENT, INTERNATIONAL LEAGUE AGAINST EPILEPSY, PAST PRESIDENT AMERICAN EPILEPSY SOCIETY, AND PAST PRESIDENT, AMERICAN ELECTROENCEPHALOGRAPHIC SOCIETY

Mr. name is Dr. David Daly. I am Professor of Neurology at Southwestern Medical School, University of Texas Health Science Center at Dallas. In the past I have served as president of the American Epilepsy Society, president of the American Electroencephalographic Society, chairman of the Subcommittee on Service and Service Training of the National Advisory Committee on the Epilepsies, and as a scientific consultant to the National Institute of Neurological Diseases and Stroke. Currently, I serve as president of the International League Against Epilepsy, a world-wide federation of professional societies concerned with epilepsy, and as chairman of the Professional Advisory Board of the Epilepsy Foundation of America.

The present hearings represent a continuing concern for epileptic persons upon the part of the Congress, a concern extending back some 30 years. In 1945, Dr. William Lennox, whose name is synonymous with epilepsy, testified before a committee of the House on the needs of epileptic persons and urged the establishment of a national epilepsy center. In 1950, Dr. Lennox testified again reiterating these needs and supporting the establishment of the National Institute of Neurological Diseases and Blindness. In this same year coverage for crippled children was extended to include epilepsy; however, relatively few states took advantage of this. In 1962, the Neurological and Sensory Disease Control Program was established within the framework of the National Center for Chronic Disease Control. This program funded several pilot studies to develop comprehensive care for epileptics. Unfortunately, the program was abolished by administrative order in 1968. In 1966, under the impetus of Secretary Celebrezze, a National Advisory Committee on the Epilepsies was established. In acknowledgement of the complexity of epilepsy, the committee consisted of a subcommittee on research and research training and a subcommittee on service and service training. Again unfortunately, the latter subcommittee was short-lived, terminating upon the abolition of the Neurological and Sensory Disease Control Program. In 1968, the Epilepsy Foundation of America arose from the merger of several voluntary health agencies concerned with epilepsy. 1970 witnessed the passage of the Developmental Disabilities Service Act. This represented a significant step forward although only a minority of the funds was expended for epileptic persons. In 1973, the National Institute of Neurological Diseases and Stroke (NINDS) initiated study of a Comprehensive Care Program for epilepsy. At the present time NINDS has funded 11 feasibility studies for the development of such a program.

In the light of these efforts, what remains to be done in the struggle against epilepsy? My answer is that major tasks still face us. The nature of these tasks can best be understood by looking at the complex nature of epilepsy, and let me speak of this. Like cancer, epilepsy is a collection of diseases with diverse causes. If the essence of cancer is the uncontrolled multiplication of cells in the body, then the essence of epilepsy is the periodic, uncontrolled, excessive discharge of nerve cells in the brain. A wide variety of diseases can cause this excessive discharge. The list includes developmental defects of the brain, infection, head injury, tumors and stroke, to name only a few. Hereditary factors have received much, perhaps too much, attention but probably play a significant role only in a minority of patients.

Epilepsy may begin at any age, from the newborn infant to the aged person. However, the greatest incidence is in children, perhaps reflecting a particular vulnerability of the maturing brain. I use the term *incidence* in the epidemiologic sense, meaning the number of *new* cases per 100,000 population in any given year. Epilepsy is also a chronic disease, often lasting through the patient's entire lifetime although not shortening the life span. Thus, the *prevalence*, that is the *total* number of cases per 100,000 population, is much greater than the *incidence*. This chronicity of epilepsy compounds our problems since epilepsy, thus, extends across the patient's educational and occupational years.

In many patients with epilepsy the underlying brain disease causing the seizures may also cause associated neurological impairment. For example, it is well known that a quarter to one-third of children with either cerebral palsy or mental retardation also suffer seizures. However, in many patients more subtle associated defects may go unrecognized. Let me cite an example. I have as a patient a young woman whose seizures begin in the visual area of the brain. The seizures begin with a distortion of vision followed by an inability to recognize either letters or words and then a brief period of confusion. Coincident with the onset of her seizures, her school work deteriorated markedly and this was attributed to the sedative effects of medication. Her parents took her to several physicians, including a neurologist, who treated her seizures, but none recognized that in the intervals between her seizures she suffered from a defect in the comprehension of written language. As a result, she left college after failing the first year. Careful testing of language function by the speech pathologist in our epilepsy group disclosed this defect. We counseled with her advisor at college and devised a modified program of studies which ameliorated this handicap. The happy ending to the story is that she will graduate from college next year as a speech therapist, perhaps with a better understanding of patients' problems because of her own.

Epilepsy is one of the last of the socially stigmatic diseases. Public opinion polls over the past two decades indicate a significant improvement in the attitude of the public towards epileptic persons. Nevertheless, major hurdles remain. The social stigma continues to impair the education of children and the employment of adults. While punitive laws restricting the marriage of epileptics have disappeared, epileptic persons still face major hurdles in entering many career fields, in obtaining insurance, and in licensure to operate motor vehicles. The cumulative impact of these many problems, particularly in the maturing child, may result in a secondary disorder of adjustment which can be as disabling as the seizures themselves.

Summed up, we may say that seizure disorders often go too long undiagnosed; some epidemiologic studies suggest an interval of several years between the onset of seizures and the definitive diagnosis of epilepsy. The seizures themselves are often inadequately treated and accompanying neurological deficits unrecognized. The disruption of the patient's way of life by this chronic disease may lead to severe educational and occupational disability.

If we are to conquer these problems, let me suggest areas in which we must move forward.

1. We sorely need a comprehensive care program for epilepsy. This must be much more than simply a better utilization of existing knowledge and facilities. Instead, it must be a *system* which will:

- Provide better health care delivery.

- Recognize and attack the educational and occupational disabilities.

- Address itself to the as-yet unsolved problem of providing continuity of care for a disease which may well persist throughout the lifetime of the individual.

To accomplish these tasks will require coordination and cooperation of the many agencies involved with the epileptic person. Surveys made in several states by the National Advisory Committee showed a dismayingly widespread lack of such coordination so that patients frequently circulated slowly and fruitlessly among the agencies. Resolution of this complex problem will obviously be one of the many important tasks of the proposed commission. The goal of such a comprehensive care program should be to provide adequate diagnostic and treatment resources for all epileptic persons.

In addition, a need exists for facilities with advanced techniques in diagnosis and treatment. In my opinion, these facilities must have residential capability since the complex of problems which beset the epileptic person do not arise overnight and cannot be solved overnight. In my capacity as president of the International League Against Epilepsy, I have had the opportunity to study the approaches to the problem made throughout the world. Norway has established a National Hospital for Epilepsy. To it come the most difficult patients who may remain for weeks or for months. During this time children attend school within the hospital and adults receive vocational training. Upon the patient's return home the National Hospital maintains contact through the local physician and stands ready to offer further assistance or rehospitalization as needed. An analogous institution exists at Meer en Bosch in the Netherlands. In Great Britain, as a result of the Reed Report, the government has mandated the estab-

lishment of regional epilepsy centers geographically dispersed across the country. In the United States, the Veterans Administration is establishing a series of regional epilepsy centers. These will have advanced technologies including resources for continuous radio telemetry of the electroencephalogram, video recording for the precise observation of seizure patterns, and gas-liquid chromatography for the accurate determination of serum levels of anti-epileptic drugs. Since such capabilities exist in this country, I believe they should be available to all epileptic persons according to their need.

Long-term institutionalization is required for only a small minority of epileptic persons. Earlier in this century many states had special hospitals for epileptic persons needing custodial care. Unfortunately, in recent years this trend was reversed, leading to the closure of such institutions and the mingling of epileptic patients with psychotic and retarded patients. On the balance this has led to a deterioration in the care of these persons needing institutionalization solely because of uncontrollable seizures. The proposed commission may very well seek to reverse this trend.

2. We need much better application of our existing knowledge. Firstly, there is an insufficient number of people involved in the care of epileptic persons. Many physicians, including neurologists, have relatively little interest in the epileptic patient. We need to improve the teaching about epilepsy to medical students and to residents in pediatrics, internal medicine and neurology. But to do this requires more people highly trained in this complex area. At the present time, it is difficult to find neurologists trained in epilepsy to head the regional epilepsy centers in the Veterans Administration. We also need many more well-trained people in the allied health sciences, for example, electroencephalographers, EEG technologists, neuropsychologists, social workers and vocational counselors. To accomplish this will require the appropriation of funds and the establishment of training programs. This, I would submit, is a matter of the greatest urgency.

We also need to provide opportunities for practicing physicians to update their knowledge and keep abreast of current progress. Gas-liquid chromatography (GLC) provides a means for the rapid and precise determination of blood levels of anti-epileptic drugs. Utilization of this technique leads to a marked improvement in seizure control and reduction of dose-related intoxication. Unfortunately, many physicians do not know how to utilize the results of GLC determinations. Beyond this, in many communities the procedure is not available and there is also disturbing evidence to suggest that some laboratories are supplying unreliable results. Thus, an urgent need exists to extend the availability of GLC technology and to assure the reliability of the determinations.

The flood of medical publications makes it difficult to keep abreast of knowledge. NINDS wisely recognized this and supported the establishment of epilepsy abstracts which attempts to summarize and categorize publications in the field. This publication has now become self-supporting. In the framework of comprehensive care a need exists for ready access to new information particularly by the advanced care facilities. NINDS has again led the way by establishing computerized information search and retrieval system. This system makes possible the automatic search of both title and text in the thousands of epilepsy abstracts. Unfortunately, this system is currently shut down because of lack of funds. The proposed commission will surely address itself to the entire problem of availability of dissemination of information and would, I hope, recommend reactivation of the epilepsy information system (epilepsy abstract retrieval system or EARS).

3. Finally, in the area of basic research, fundamental questions about epilepsy remain unanswered. This year, for the first time in 14 years, a new anti-epileptic drug, carbamazepine, will be introduced in the United States. We need to accelerate drug development and we need to know much more about how anti-epileptic drugs work. Clinical testing of new drugs has often lagged because of the difficulty in obtaining carefully studied groups of patients on whom to try new drugs. Implementation of the comprehensive care program would do much to alleviate this problem.

A need exists for systematic screening of potential anti-epileptic drugs and this, in turn, suggests a need for a better understanding of their mechanisms of action. In turn, we need a deeper understanding of what makes nerve cells epileptic. Many of the experimental models of epilepsy involve physical or chemical injury to the brain, for example, the "freeze" focus or the alumina-cream

focus. A more recent technique of electrical stimulation called "kindling" offers a new direction. In experimental animals kindling seems to be prevented by the administration of some anti-epileptic drugs but not by others. Clearly here is an important clue to the mechanism of action of drugs.

Paradoxically, we cannot answer the seemingly single question: how many persons have epilepsy? Using available data, one can project from 1 to 4 million persons in the United States. In general the more recent and more carefully conducted epidemiologic studies yield higher prevalence figures. However, to answer our question reliably requires far more extensive studies. The results of such studies would do much to define one of the dimensions of our problem.

Let me conclude by saying that epileptic persons constitute a silent and often hidden constituency. The actions of the Congress over the past thirty years express a recognition of their needs. However, this constituency itself has often not made vocal the full extent of its needs. This we are attempting to do today in the hope that the establishment of a National Commission will lead to a focusing of our resources and capabilities. Compelling humanitarian reasons exist for our doing this. But in addition, restoring epileptic persons to a useful existence will, by making them contributing members of our society, economically repay itself many times. To paraphrase Winston Churchill, in few diseases will so small an investment do so much for so many.

Thank you, Mr. Chairman, for this opportunity to appear before the committee.

Mr. KYROS. Thank you, Dr. Daly.

Mr. Preyer.

Mr. PREYER. Thank you, Mr. Chairman.

I noticed Mr. Funk's figure that the cost of epilepsies to the Nation is \$4.3 billion a year. How do you measure that? Dr. Daly touched on loss of usefulness and lives.

Mr. FUNK. The methodology is outlined in the report itself published by the foundation, I believe but very simply it consisted of going to scattered Federal records in many, many places and attempting to put them together into a coherent whole.

Mr. PREYER. I think that is a very important figure. I would hope for the sake of the record we could put all the methodology in to back that up.

[The following information was received for the record:]

#### MEASURING COST OF EPILEPSY

The percentages and per capita costs utilized in the "Cost of the Epilepsies" study reflect the figures taken from state and federal data relating to a wide range of social, medical and rehabilitative services. To list but a few: physicians' fees, costs of institutionalization, special education, vocational rehabilitation, unemployment, wage and hour loss, and veteran's benefits. While there are many more factors involved in the estimate of the cost of epilepsy, only those statistics readily available from government and other authoritative sources were utilized. The estimated total cost was derived in the following manner: The prevalence rate of epilepsy of four million (derived from U.S. Public Health Services Publication No. 72-323) or approximately 2 percent of the U.S. population was applied to each of variables except in categories where more specific data was available as outlined in the report entitled "Cost of the Epilepsies."<sup>1</sup> Each of the fourteen areas examined in the report contain the rationale for arriving at the estimated dollar amount. As a final step dollar estimates for each category were added together. While the methodology is, albeit simple, this is the best estimate made to my knowledge in trying to determine the cost of epilepsy in order to provide some understanding of the scope of the economic implications.

Mr. PREYER. One of the things I think we fail to consider too often in legislation, particularly in health legislation, is how much we save

<sup>1</sup> "The Cost of the Epilepsies to Individuals, Families, and to the Nation," a report assembled by the Epilepsy Foundation, may be found in the committee's files.

by spending. We have the family planning bill on the floor today and there will be a lot of complaints about its spending levels.

And yet, the cost-benefit ratio for family planning services works out to a savings of \$2.50 to \$2.90 in the year following an expenditure of only \$1. So really you are spending to save, and this \$4.3 billion figure, I think, can be translated into a very substantial saving from a relatively modest expenditure. Consequently, I hope that this figure be developed and sustained methodologically, and proved to be methodologically sound.

I notice you also cite in 1963 when Mr. Celebrezze was Secretary of HEW, there was a Secretary's meeting on epilepsy. Was that in the nature of a conference on epilepsy?

Mr. FUNK. I would defer to Dr. Daly, who I think was involved with that effort.

Dr. DALY. It is my understanding—I was not a participant in this, Mr. Preyer—but it was my understanding, Mr. Celebrezze met with a number of concerned lay persons about epilepsy and they transmitted to him their feelings about the needs that existed. As a result of this he established the Secretary's National Advisory Committee on the Epilepsies, which consisted of two subcommittees, a Subcommittee on Research and Research Training and a Subcommittee on Service and Service Training.

The Subcommittee on Research endures in the present National Advisory Committee of NINDS. The Subcommittee on Service and Service Training was abolished.

Mr. PREYER. I was interested in the regional epilepsy centers that you mentioned, Dr. Daly. You say they have established those in Great Britain.

Dr. DALY. Yes, sir, the British Government established a commission and the upshot of this was the Reid report which took cognizance of the fact there was no national plan in Great Britain for the management of epileptic persons who face problems similar to those in this country. One of the recommendations was the establishment of regional centers of special capability.

Mr. PREYER. Do you know how many are set up, how large they are, and what the funding is?

Dr. DALY. I believe at the present time there are four of them. They are still in the process of establishing them. Each has institutional capability, I believe, for about 130 persons.

Mr. PREYER. It might be interesting to see what they have done and how it has worked out.

I enjoyed your testimony, Mrs. Grass, and I found your letter particularly moving. I think all of this testimony is very helpful and interesting.

It appears clear that there is not any question about it that epilepsy is not a disease like sickle cell anemia or mumps or measles. It is more analogous to cancer. It is a collection of diseases coming from various causes. Therefore, we are not going to find any magic answer to it. It is going to take a long pull and a lot of basic research, isn't it?

Dr. DALY. I would agree.

Mr. PREYER. Thank you very much.

Mr. KYROS. Thank you, Mr. Preyer.

Mr. Hudnut.

Mr. HUDNUT. Thank you, Mr. Chairman.

I appreciate the testimony that has been offered so far. I am sorry I was a little late. I just got in from Indiana.

I was going to ask the same question that my distinguished colleague on the other side of the aisle asked relative to the cost estimate of \$4.3 billion, which is to a layman like myself astounding. I do not think that most Americans, 99.44 percent of them, have any comprehension of the magnitude of the problem that we are addressing ourselves to or the cost to the American people. You say in your testimony, Mr. Funk, that you will not elaborate upon the study as it has appeared in the Congressional Record, but I wonder if just for our records you could indicate briefly how you or the people that did this study on the cost of epilepsy to the Nation computed the figure of \$4.3 billion.

For example, aid to families with dependent children. It is amazing to me that in the ADC program \$53 million can be traced to epilepsy. I wonder how you came up with that or with the \$4.3 billion figure.

Mr. FUNK. How we arrived at the \$53 million figure is something I am not competent to answer today, but I would be happy to get you that answer from the complete study.

Mr. HUDNUT. With the chairman's permission would it be all right to request documentation of how they arrived at these various different figures and computed them and submit it for the records.

Mr. KYROS. It is so ordered without objection.

[The following information was received for the record:]

The \$53 million figure as a result of epilepsy as it relates to the A.D.C. program was derived in the manner shown on pages 11 and 12 of the "Cost of the Epilepsies" report and is attached.

#### AID TO FAMILIES WITH DEPENDENT CHILDREN

AFDC serves families with children who are deprived of parental care and support. For example, one of the parents may be absent or incapable of supporting the children due to some disability. In cases where the father is at home and is disabled, epilepsy is the main disability in 5% of the cases. National data are not available on the prevalence of epilepsy among mothers and children in the AFDC program.<sup>1</sup>

According to the 1971 HEW survey, fathers were present in 472,000 homes receiving this type of aid (or 18.7% of the total family cases).<sup>2</sup> We can, therefore, project that approximately 23,645 families receiving aid to families with dependent children have fathers with epilepsy. As of June, 1972, the average per-family payment was \$187.40 monthly.<sup>3</sup> It follows that persons afflicted by epilepsy would claim \$4,431,073 of the monthly \$536,063,000 expended to recipients in this program. On this basis the annual cost attributed to epilepsy among families with fathers in the home is \$53,182,876. This estimate is based upon only 18.7% of the recipient families and, as such, is a minimum projection of the cost of epilepsy to the total AFDC program.

#### SUMMARY

Percent of AFDC fathers with epilepsy-----	5
Number of AFDC families with epileptic fathers-----	23, 645
Average monthly grant-----	\$187. 40
Estimated cost to AFDC-----	\$53, 172, 876. 00

<sup>1</sup> Winston and Chillman.

<sup>2</sup> Findings of the 1971 AFDC Study. Part I: Demographic and Program Characteristics, U.S. Department of Health, Education, and Welfare (Washington, 1971).

<sup>3</sup> Public Assistance Statistics, June 1972.

Mr. HUDNUT. Thank you very much. One other question.

Mr. Funk, you estimate in your testimony that the cost for this Commission would be somewhere between \$200,000 and \$300,000. It is a nine-member Commission. They will have a lot of work to do, but that does strike me as a little high. Is there any background you could give us regarding how you arrived at that estimate?

Mr. FUNK. I have a very rough budget that I would be glad to submit for the record, because I have it here today. The cost actually would depend on the manner in which the Commission elected to go about its activities and to a considerable extent the amount of information available to it from other organizations which was acceptable to it as to its completeness.

So the figure in my testimony is very much an estimate and I think the real answer perhaps would come from the Commission itself.

Mr. HUDNUT. Again, Mr. Chairman, if you would be willing to let him submit this for the record in answer to my question, I would appreciate it, as to how he estimates the cost of the Commission as between \$200,000 and \$300,000.

Mr. KYROS. It is so ordered.

[See "Aid to Families With Dependent Children," p. 60, this hearing.]

Mr. HUDNUT. One general question, if you forgive a personal reference. I have a brother—who incidentally, Mrs. Grass, went to Princeton as I did. He had an automobile accident when he was just 1 year old. A car ran over him and fractured his skull.

When he was 35, he was attending a church service in Colorado and just for no apparent reason flipped out and went down on the floor in the pew in front of him and began writhing around. Within a very short period of time it was all over, and never recurred, but this dramatized for our family the kind of incipient epileptic problem that you have described. Of course, it was an embarrassment to him, and I am wondering if you could just briefly expatiate on the embarrassment or the social stigma that the American people still associate with this disease.

It is not a national disgrace that a person has a disease of epileptic nature, but it is a national disgrace that people think it is a disgrace to have the disease. I wonder if any one of the panel could briefly address himself or herself to the problem of the social stigma involved with this and how perhaps a national plan might cope with that.

Mr. FUNK. What you say is very true. I believe that later today some of the people who personally have the problem will probably be more revealing and their testimony will be more meaningful than mine. But in a classroom the reaction of a teacher, the reaction of classmates, has a very real bearing on how the child is accepted, as to how its attitudes are formed and how its approach to life is formed.

I would say this. Even some of our national directors, many of whom are people of prominence in the Nation, many of them who have worked with us for years have only recently at long last and very carefully told us that they have epilepsy. And that fear speaks for itself. I know of one man, a vice president in a bank who decided the time had come to speak out.

He felt that if we are going to do away with stigma and discrimination, we will do so only when individuals stand forth. But he learned

in a very painful way that the time has not yet come. That experience has been painful to him in the company that employs him because they have doubts and they do not realize that these doubts are groundless, that the man is incapacitated for a few minutes every several months only.

There are questions as to "what is wrong with him, why does he act like that, what is this all about?" So whether it is getting a job, whether it is holding a job, whether it is the reaction of friends and the community, stigma is very real.

Dr. DALY. May I supplement that remark?

For 3½ years I operated a minicomprehensive care program in Phoenix in part of the Barron Neurologic Institute. We had a program involving the entire school system in Phoenix. We found that most often the stigma related to lack of understanding. Teachers were fearful that something would happen to a child who had a seizure in class. Some of them feared the child might die.

We found that if we could provide rational medical and physiological explanations to the teachers, the problems in the classrooms subsided. When we could talk to the other students and explain to them the nature of this illness, the problem subsided. When we could talk to the parents of children who had major misapprehensions and were fearful to have their own children play with children who had seizures, the problem subsided.

So these are not insurmountable problems, but they take a determined effort and a plan. We cannot find a simple solution in a medical setting. We need more than that for a comprehensive care program.

Mrs. GRASS. May I also respond to Mr. Hudnut?. I have an international view which may be helpful to you.

In Nigeria, for example, epilepsy is considered contagious. It is considered as emanating from evil spirits who take possession of a person and need to be exorcised by a medicine man. Fortunately we are a bit advanced beyond that, but not appreciably because I think some of these basic fears which have come up over the ages persist.

We gloss them over in a sophistication, but they still persist. As a public speaker for epilepsy here and there I often see women in the audience with their hands over their mouths whispering to the person next to them. "Why do you think she is talking for epilepsy? She must have it or one of her sons must."

Neither is the case. I was one of these children who had ferbible convulsions and who never got anything else. But the fact that one associates with the cause and therefore is labeled is one of the problems of epilepsy and I would like to say in advance that the courage of our consumer panel who will appear before you later this afternoon is extraordinary.

Mr. KYROS. Let me ask you a question. The Commission on Multiple Sclerosis that you worked on, has it published a report?

Mrs. GRASS. Yes, sir; it is a two volume report.

Mr. KYROS. Did you find that commission form, which worked throughout the year, instead of a conference, which had been suggested for a 1-week study of epilepsy, which is the administration's viewpoint, costing about \$50,000—do you think that the commission form was better?

Mrs. GRASS. The commission structure was a small group like an executive committee which included among other people three medical school deans of prominence. I believe the attendance—although we met one a month—was nearly 100 percent. It has enormous interest in this problem.

Mr. KYROS. Do you know the cost of that commission? That is not normally within your province, but do you have any idea?

Mrs. GRASS. No, sir; I had nothing to do with the accounting for expenses.

Mr. KYROS. I believe it was about \$200,000.

I thank this distinguished panel for extremely enlightening and moving statements.

Our next panel is a consumer panel of people who are directly affected by epilepsy. I think it is a service to us that these people have come here as citizens to testify and to indicate the kinds of problems that occur.

We are pleased to have with us a close personal friend of my daughter, a lovely young lady, Miss Martha Mittendorf, from Alexandria, Va.; also Mrs. Cathy Root, Miami Lakes, Fla. Mr. Cal Williams, Culver City, Calif. and Mrs. Allison Logan Belcher, Portland, Oreg.

Martha, we are pleased to have you here at the committee. I understand you have a statement.

#### STATEMENTS OF CONSUMER PANEL:

**MISS MARTHA MITTENDORF, ALEXANDRIA, VA.;**

**MRS. CATHY ROOT, MIAMI LAKES, FLA.;**

**CAL WILLIAMS, CULVER CITY, CALIF.; AND**

**MRS. ALLISON LOGAN BELCHER, PORTLAND, OREG.**

Miss MITTENDORF. Mr. Chairman, I sincerely appreciate having this opportunity to appear before you to discuss a matter of great personal concern to me, and to support this subcommittee's bill to provide for the formation of a commission to study epilepsy and suggest legislative actions to close the misinformation gap surrounding this affliction.

Mr. Chairman, there is a need for Federal assistance in this area, and I understand that the precedent has already been established by Congress, most recently by enacting similar legislation pertaining to multiple sclerosis. I also feel, Mr. Chairman, that there is a definite need for a central clearinghouse concerning epilepsy, which the commission certainly would be in the sense that following their report to Congress, much more information would be available to the Members of the legislative branch than is now the case concerning the physical and mental aspects of this disability.

I would like to cite for you some of the problems which most concern me, and I am hopeful that my doing so will help in your consideration of the proposal before you.

I am 17 years old, and I have been an epileptic for 11 years. Even though I have personally experienced epileptic seizures, both petit mal and grand mal, I do not know the specific causes or cures for this

affliction. I do not know if anyone knows all the causes and cures, but I certainly think it is necessary to find out more about this disability.

In years past, especially in grade school, my classmates labeled me as an outcast, not because I enjoyed my schoolwork, or because I like to play too much, but because I would have seizures during school. My seizures were different from what my fellow students had ever seen or known, and therefore, beyond their understanding. Perhaps they were frightened by what they saw. In any case, my seizures continued, and I was constantly mocked.

I point this out, gentlemen, because during the early years of my development, the impact of my fellow students' opinions of me was much greater than it is now. A classmate can be cruel, but the cruelty of a whole class can be almost unbearable. With no one to turn to, a person tends to turn inward. And a person only regarding oneself is not a very productive member of society. But I really believe that had my classmates known more about my affliction, they would have treated me as an equal.

Despite all this, I consider myself lucky. For I have been blessed with a family having not only the means, but also the understanding to help me deal with my problem, to realize that it doesn't have to be a permanent barrier to leading a full and happy life. But I know that other children are not so lucky. I have had access to the best medical treatment available, but I wonder what happens to the hundreds and thousands of children whose parents either don't understand their problems or don't have the financial resources to give them the kind of advantages I have had. This is something, Mr. Chairman, that I know you and the members of the subcommittee will want to think about, and this is one of the reasons I feel a National Commission on Epilepsy could be so helpful.

I have told you, gentlemen, a little bit about my own personal difficulties for a reason. I believe that, with sufficient information about epilepsy, perhaps through a media campaign directed at young people, most of the misinformation about epilepsy would be dispelled. I hope that this will be one of the findings of the Commission established in Mr. Kyros' bill. For, if the things I have talked about come true, I believe many people now suppressed and hidden will prove excellent and very productive members of society.

Thank you.

Mr. KYROS. Thank you.

I would like to add here that Martha's dad is Secretary of the Navy in this country. So, we are very pleased to have your testimony here, and we will continue as a panel before we do any questioning.

Our next witness is Mrs. Cathy Root.

#### STATEMENT OF MRS. CATHY ROOT

Mrs. Root. First of all, I would like to point out, extemporaneously, it is nice to know that the Health, Education, and Welfare Department has so much money—but my husband and I have not benefited from any social agency whatsoever, and we have had nothing but a financial struggle since we discovered our child had epilepsy.

Now, I am prepared to give my testimony. My daughter, age 9, has epilepsy. She has had grand mal convulsions since she was 21 months

of age. When we were told she had epilepsy, we were relieved. We had no idea of the future which was ahead of us, especially in dealing with society's total rejection and lack of knowledge about epilepsy. We had no idea of the overwhelming cost head of us.

The medical costs for a child who has epilepsy are staggering at times. Not until recently were we able to get hospitalization insurance for our child, so our savings are totally exhausted from many hospitalizations. A child with epilepsy, such as our daughter, does not get a simple cold—she gets a fever and convulsions with her runny nose, and this necessitates either emergency treatment or some kind of hospitalization. Our daughter almost died from a case of chicken pox and again during a simple tonsilectomy. Needless to say, the hospital costs with no insurance were tremendous. Today, as a parent of a child with epilepsy, I fully realize the extent of the overwhelming financial cost involved.

Not only do you have medical costs, but you have side effects from your medication, which requires special, other medical costs not involved with the epilepsy.

Our major problem today is our daughter's reaction to peer pressure and her intense dislike for school. Our child goes into fourth grade this year. Since first grade, she has shown signs of intense dislike of school and discomfort in peer pressure. After my conference with teachers and school psychologists, it was decided that we should wait and see what would happen—time would tell. Eventually, she was given IQ and psychological testing, within the public school system, and we were advised that she had a learning disability in math. We were assured we should not be concerned about this, as she did well in reading. For 2 years, she brought home average report cards and school for her was a nightmare.

Finally, in one visit to the child psychiatrist, we discovered she had a severe learning disability, and for the 3 years she had been in school, she was unable to comprehend or understand anything that she had tried so desperately to learn. If there had been funds available 3 years ago or if the testing services available within the school system had been more adequate, our child would be functioning normally in school today. Her psychiatrist informed us that had she waited 1 more year, she would no longer be able to perform in school at all. Here self-esteem would have been critically damaged and remained so for the rest of her life, compounded by the fact of her epilepsy.

There are programs and moneys available for mental retardation, cancer, heart, and other ailments, but the person with epilepsy has no place to go—many cannot even get on welfare. How many adults with epilepsy today are uneducated and untrained for any type of life because they may have had a learning disorder which prevented them from obtaining a proper education, to which they have a right under the law. How many of today's children who have epilepsy, will be tomorrow's school dropouts as my child would have been? I ask that you at least give the children with epilepsy a chance for tomorrow.

Our child is a beautiful child—both within and without—my husband and I have sought, to the best of our capabilities, to preserve and enhance that beauty. We realize that we were fortunate to discover our daughter's problem, even at this late date. It may be of interest to

note that remedial educators refuse to take children who are older than 8 years of age. Now, we will receive supportive remedial education, which will be a long and costly process.

My point is simply this; it is not just a question of diagnosis, it is a question of quality diagnosis. How many children are in this country who have been improperly diagnosed both educationally and neurologically because their parents lack the money? How many children are there with seizure problems that could be properly treated and controlled if there were financial resources available for their parents? Children with epilepsy do not need services, they need quality services, a quality service which parents can rarely afford to give them.

I have personally talked to and visited with well over 100 persons who have epilepsy. Although most of them have good seizure control, they were totally uneducated and untrained to lead a normal life in a society which has rejected them since they were children. After talking with so many persons and realizing that most of them had the same problems, no education and no training, I thought that somehow their parents had failed them. Now I realize that their parents did not fail them—they did the best they could with no financial assistance anywhere. I realize now that if financial assistance had been available to those parents, the children, who are now adults, would be living a normal life with feelings of pride and self-confidence.

I no longer tell anyone that our daughter has epilepsy. I hope to safeguard her from the stigma of epilepsy. Many people, I am sure, feel that epilepsy is an accepted condition nowadays—but this is not so. Children are prevented by their parents from playing with my child, because she has fits; adults don't want her around, it makes them nervous, and I, myself am not acceptable to be a scout leader because my daughter has epilepsy. The list of discriminations and rejections is lengthy.

I know I have to continue my efforts on my child's behalf, as must all parents of children with epilepsy, no matter what the cost of our efforts may be: I will do the best I can. But I need your help. We need your help so that my child and others like her will have a chance that many adults, with epilepsy today, never had, namely, the opportunity of receiving quality diagnosis and treatment that will allow them normal living.

Mr. KYROS. Thank you for a very moving statement. I certainly appreciate the fact that you came all the way from Florida to give us this statement, and it certainly answers a lot of questions about the question of social stigma, which is so difficult to talk about. We appreciate it.

Now, Mr. Williams, welcome to the committee, and will you please give us your statement?

#### STATEMENT OF CAL WILLIAMS

Mr. WILLIAMS. Thank you.

I would like, if I could, Mr. Chairman and members of the committee, to depart a little from my statement. But I would like to give a special thanks to you, Congressman Kyros, for the letter dated July 29. I thought it was one of the most insightful letters I have ever seen in terms of the problems confronting the epileptic.

I would like to address myself more from the job that I have than the circumstances of my seizures, because my job is dealing with other people's seizures.

I am now the manager of EPIHAB, a rehabilitation program for epileptics. This program became necessary when other workshops and other programs did not present opportunities to the people who had epilepsy to go through the work evaluation and work training. The Department of Vocational Rehabilitation, whenever they get an epileptic in their program, their first thing is to call EPIHAB, and we used to do evaluations for the Department of Vocational Rehabilitation, but we wanted them to send us the epileptics because we felt they were the ones who were grossly discriminated against and there were no services available for them.

Mr. KYROS. This is the Department of Vocational Rehabilitation of the State of California?

Mr. WILLIAMS. I get calls from all over the United States from other Departments of Vocational Rehabilitation Councils as to what shall we do with this person.

The reason they gave for not wishing to accept the epileptic is a vocational counselor is measured in this performance in terms of how many successful closures he is able to get. They felt that an epileptic would not be anymore placeable after training than he was prior to training, and so, there was a greater inclination to use our shop for other disabilities rather than for the epileptic.

I have appeared at many institutes to tell about our program EPIHAB. In our program, we have people working in electronics. We have epileptics working on lathes, milling machines, radial saws, all of the equipment that is almost an anathema, when you think of the word "epilepsy."

I wanted to bring this up because I am a little disappointed in the moneys and the efforts that are being spent by the Department of Vocational Rehabilitation and also Health, Education and Welfare—and, incidentally, this book that they have here—it is one of the few books they have—and each one of the people in there are people that I trained. I placed one of them in there as dead, but this shows our workshop—and when we try to get funding for our workshop as a single disability workshop for epileptics, they would not grant it, because they said they had to give the services to other disabilities even though other workshops could reject an epileptic as not being feasible for their program. So, we had to discontinue subsidy, the evaluations we were getting from the Department of Vocational Rehabilitation, because we wanted to work with the epileptics.

But getting back to the problem I want to stress. I think they are doing a very poor job because many of the people that are included in the epileptic problem are people who are trainable and placeable. There is nothing necessary to do except to educate the public.

I am disappointed at the medical profession. Though they have gone through all of these years of developing drugs and controls, people have the same fears and apprehensions of epilepsy today that they had many years ago, and this is not right. It is not justified with the information available.

An epileptic, whether he has two seizures a year or two a month or two a day, he is an epileptic and he is given the same carte blanche

treatment, which means we compound our problem of trying to find an overall solution where the answers will not be the same for each person.

Until such time as we undertake to try to tell the American people—I think I had in my statement that in Los Angeles they were discussing whether or not we should have a bare beach—this is something we can talk about. Twenty years ago we could not have dared to talk about that. But still, epilepsy is something that must be whispered.

I never felt such degradation—I used to have three and four seizures a day, maybe 2 or 3 days a week, and I never felt such degradation, such patronizing, as though I were some raving, mad idiot, I was incapable of making decisions for myself, and this multiplied the seizures. I was totally depressed.

I think if there is a commission, there ought to be an effort to try to stabilize the categories of the seizures in this sense, that there are some people who do have medical remissions, and efforts should be made to try to codify an acceptable degree of control for placement. Efforts should be made to codify an acceptable degree of lack of control to receive public benefits. Efforts should be made then to try to get the solution for those people who cannot benefit who do not have seizure control.

This is the thing that EPIHAB is trying to do. We have placed over 1,500 people in various positions. We are a nonsubsidized program. I had to borrow \$4,000 to make my payroll before I came here, but we are a nonsubsidized program and we are placing people, but it is on a 1-to-1 basis.

We do not have the resources for this massive placement that is necessary. How we place people—we go into the company, we explain to them what the seizure phenomena is. We explain to them what they must expect, what they should do if a seizure should occur; and we find once they have some understanding of the seizure, the seizure is then acceptable and tolerable.

[Mr. Williams' prepared statement follows:]

#### STATEMENT OF CAL WILLIAMS, CULVER CITY, CALIF.

Mr. Chairman and Members of the Committee, I wish to thank each of you for your kindness in giving me the opportunity to appear before this Committee.

I would like to give special thanks to Congressman Kyros for his letter dated July 29, 1974 address to his colleagues. It stated the problems facing the epileptic well and I pray for your success in the enactment of H.R. 13405.

I am an epileptic. I have grand mal seizures. It is post traumatic epilepsy as a result of head injury sustained in World War II. The injury was sustained in 1944; however, it was not diagnosed as epilepsy until March 1948. Prior to the diagnosis of epilepsy the doctors called them blackouts and I was having them at the rate of 3 or 4 per week. I was in Letterman General Hospital being treated for another injury approximately six months before I was diagnosed as an epileptic. I was allowed to participate in any activity I desired—swimming, gym, field trips and everything else. But the day I appeared at staffing and I was officially declared an epileptic as if by magic every activity off the ward was curtailed unless someone signed me out and accompanied me. I wasn't allowed to go on passes, I couldn't go to the gym, suddenly I was treated as if I were incapable of making the same judgments I had made when my seizures were called blackouts.

When I questioned the doctor about these restrictions and reminded him that I wasn't having any more seizures than I was having blackouts and he did not object to my activities then, why now? The doctor stated that I was

lucky; and besides, according to regulation I could not take part in the activities that were restricted.

The question then as now is this: are we treating the word "epilepsy" or the symptoms?

Is every person afflicted with epilepsy incapable of exercising sound judgment? Of course, we know this is not true!

At that time I knew absolutely nothing about epilepsy. I did vaguely recall a boy in my hometown that had epilepsy. They called it fits. I was told that I shouldn't bother him because of his fits. I remember some of the things said about him and now I had fits. I was confused, bitter and depressed. I wondered why I couldn't lose a leg, or arm, eye, anything but not these fits. God knows how I prayed that I could just die. If someone would have said anything to give me hope. But more and more I felt the world closing in on me. I think for certain I had an epileptic personality.

That was 28 years ago. Before man ever pierced outer space, when an alcoholic was just a plain drunk. There was no wall in Berlin or topless or bottomless dancers. These things touch our very roots and have changed our attitudes.

Or at least we can accept them. But the epileptic today faces the same rejection he faced 28 years ago.

It is not just from the general public, but government agencies. The Department of Vocational Rehabilitation is reluctant to accept an epileptic on their caseload and only those who persist will be accepted.

The employers are reluctant to hire epileptics. Landlords are reluctant to rent to epileptics. What a dilemma! We can't get public assistance because we don't qualify. We can't get medicine, so we have more seizures. If the general public and employers haven't learned any more about epilepsy than I knew 28 years ago when I first became an epileptic, is it realistic to expect their attitude to change? If we cannot inform, then we really will never see real change.

The epileptic, each in this own way, will suffer his personal hell. We must change, we must inform, we should do it now!

Mr. KYROS. Thank you very much, Mr. Williams. It is again a very informative and helpful statement to the committee.

Mrs. Belcher, from Portland, Oreg.

Mrs. BELCHER. I am going to give some extemporaneous remarks.

Mr. KYROS. We will make all your statement a part of the record [see p. 72].

#### STATEMENT OF MRS. ALLISON L. BELCHER

Mrs. BELCHER. I am Allison L. Belcher of Portland, Oreg. My son, David, now age 5, has had epilepsy since age 4 months. The diagnosis was established by the Clinic for Neurologically Impaired Children at Good Samaritan Hospital in Portland, a multidisciplinary diagnostic, evaluation, and educational facility that is unique in the United States.

I am speaking on behalf of David, my son, for he cannot speak and he probably will never be able to, but he is a person and I think he has rights and he has needs.

There is a definite message for those epileptics who will not be able to function for themselves. We in Portland are extremely lucky because we have the Clinic for Neurologically Impaired Children. When I listened to Mrs. Root, I realized how fortunate I have been, and I would like to see that all people in this country are as fortunate as we are in Portland.

This clinic was begun in 1963, and it was funded at that time by HEW along with several other clinics, but the Portland Clinic is the only survivor.

The Clinic for Neurologically Impaired Children realized that a child with epilepsy has many problems. First, frequent seizures disrupt the mental processes, and in severe cases like my son David's, the result is severe intellectual deterioration. Also, seizures can disrupt the necessary learning process. Attention span is short, especially in the young child. This can be due to the drugs, or in the other cases it is independent of the drugs.

There is often marked anxiety on the part of the epileptic child. I cannot talk about the adult, but I can talk about the child and his family, and I would like to mention here particularly siblings. My son's sisters find it difficult to explain this. They have anxieties. David is not capable of knowing his anxieties, but my other children are.

Mr. KYROS. David, your 5-year-old, what symptoms does he have at the age of 5?

Mrs. BELCHER. At 4 months he began his grand mal seizures, and he has had as many as 12 a day. He also had cerebral palsy and is mentally retarded on the level of about an 18-month-old.

For his seizures he is on medication. He has a superb doctor who heads the clinic, Dr. James Schimschock. We have been fortunate in Oregon. But he cannot speak for himself and won't be able to, so that is why I have to do it for him.

In most places, not so much in Portland, most communities do not have an effective program for people with epilepsy. Teachers, social workers, and even some doctors are not informed about the potential needs of epileptic children and adults, and I really feel that the child and the family needs an advocate.

That is why the clinic is so important to me in Portland. They are able to find out the diagnosis of the child and exactly what can be done. They have informed the community. They deal with the family problems, which are multitude. They help put the child back in the mainstream of society or have him enter the mainstream; and for my child who is chronically and severely handicapped, they have given me faith and courage to continue, and I cannot overemphasize this. I think we all need support, and this clinic and the doctors and the dedicated people there have helped.

The Clinic for Neurologically Impaired Children is an interdisciplinary team. In the clinic there is a pediatric neurologist, a child psychologist, preschool teachers, an elementary school teacher, physical therapists, and social workers. This whole group of people gather together to evaluate and then work with the children.

This clinic originally was funded by HEW, but now it is funded not only publicly but privately. Developmental Disabilities in Oregon is one of the funding sources. Our own county, Multnomah County Mental Health Department, and Portland public schools give money to it. Privately, Good Samaritan Hospital gives financial aid, as well as just people like me.

Besides the diagnosis, evaluation, and education of the child, they have something which to me is a vital part of the program, and that is parent training and help. All of us have had this nightmare of not knowing where to turn.

I remember the worst blow I had when I found out at 4 months that my child was going to be epileptic was that he would never play foot-

ball. It was at that time the most traumatic thing that ever happened to me because I happened to be a former physical education teacher, and for my son not to be able to play football was frightful. That is minor now.

But this group, doctors and teachers, care about my son. They really care about him. They work with me. They know the names of my other children, and they are happy to see them and they give them supportive help, too. That is what I cannot overemphasize.

Every community in this Nation, every community should have something like this clinic where people with neurological impairments can come and get correct diagnosis and evaluation and the help they need.

Mr. KYROS. Mrs. Belcher, I hesitate to stop your statement. It is a very fine statement of great interest. But that was a second call of the House, and we must go and answer because there are only several minutes left.

We have not finished asking all the questions of this panel, although your statements were all complete and full. If any of you would wish to return at 2 o'clock when the committee will reconvene, since it will recess at this time, we will be glad to ask you more questions.

As far as I am concerned, I want to thank you. I think it is a great public service that persons like yourselves, intimately concerned with this, should come forward and speak of your own personal experiences despite, as you said, some overriding social problems that this disease has.

Mr. HUDNUT. I would like to second what you said and associate myself with your remarks.

Mr. KYROS. We are sorry to interrupt, but we have 7 minutes left. We do appreciate the consumer testimony we have had. It is wonderful of you to come, and I have been moved by what all of you have said and I hope we can do something constructive to help solve the problem you are addressing.

The committee will recess until 2 o'clock.

[Whereupon, at 12:30 p.m. the subcommittee recessed, to reconvene at 2 p.m., the same day.]

#### AFTER RECESS

[The subcommittee reconvened at 2 p.m., Hon. Peter N. Kyros, presiding.]

Mr. KYROS. The subcommittee will come to order.

To return to the panel, I would like to ask Mrs. Belcher to continue her testimony.

Mrs. BELCHER. Do you want me to go on?

Well, I was saying that I feel that I am very fortunate in Portland having the clinic for neurologically impaired children. It works with preschoolers and mainly elementary schoolchildren, but even in Portland there are tremendously unmet needs and I think this House bill would take this into consideration; the fact there are very few vocational training programs; residential treatments are not available in many parts of the country.

Respite care is not possible for many families. They do need the opportunity for a break. I feel sincerely in order for this whole pro-

gram, for all the children in the country and all the adult population that we must have a concerted effort nationally, so we can really work to conquer this problem which has faced us for many years.

That is all I want to say and I want to thank you very much. I appreciate this opportunity.

[Testimony resumes on p. 77.]

[Mrs. Belcher's prepared statement follows:]

STATEMENT OF MRS. ALLISON L. BELCHER, PORTLAND, OREG.

Mr. Congressman, I am Allison L. Belcher of Portland, Oregon. My son, David, now age five, has had epilepsy since age four months. The diagnosis was established by the Clinic for Neurological Impaired Children at Good Samaritan Hospital in Portland, a multidisciplinary diagnostic, evaluation, and educational facility that is unique in the United States. As a parent and "consumer representative," I have prepared these remarks which outline the great needs of David and the thousands of other intractable epileptics, and document the role of the multidisciplinary clinic approach to them. The thrust of your legislation could ultimately make facilities of this kind available nationwide.

The Good Samaritan Clinic for Neurologically Impaired Children was established in 1963 as one of several such clinic funded by grants from the Department of Health, Education, and Welfare. It is the only survivor. The Clinic was to serve children with epilepsy as well children with learning and behavior problems. Epilepsy is one of the more common childhood problems. It has been the observation of clinicians over the years that many children with childhood epilepsy have associated learning and behavior problems.

These problems of the child with epilepsy can arise from several sources. Frequent seizures can disrupt mental processes and in some cases result in severe intellectual deterioration. In those cases where "subclinical" seizures are occurring, unpredictable, undetected episodes of inattention or so called "silent seizures" can disrupt the necessary learning processes which are so important during childhood. It has been further observed that many children with seizures, particularly younger children, are extremely distractable and exhibit very short attention spans. Although in some cases the short attention span may be related to medications, this finding has been observed independent of drug administration. Chronic high doses of anticonvulsants do often contribute to poor school and life experiences of children with epilepsy. The lethargy and poor coordination associated with the chronic use of anticonvulsants is well known. Although methods for detection of blood levels of anticonvulsants are now available, the clinical application of these techniques are only now being explored.

In addition, children with seizures, particularly uncontrolled seizures, often develop marked anxiety. This is often dealt with ineffectively by the parents, who have not resolved their own feelings about their child's illness. Frequently, the child's questions go unanswered and the family is unable to deal effectively with the full emotional implication of the child's illness.

The most effective medical management depends upon the cooperation between the parents and the community on one hand, and the treating physician on the other hand. Although close medical supervision is now more effective with the advances in serum drug analysis, and the few newer anticonvulsants which have come available, the information about the child's actual adjustment to his living circumstances and his successes or failures in the work of childhood (learning) does not reach the physician. In many instances, the social adjustment of the child with epilepsy presents a more serious challenge than the manipulation of anticonvulsants.

With few exceptions, community resources do not provide effective programs for children with epilepsy. Few teachers are adequately informed about the potential needs of these children. The "epileptic child" is often treated as a potential "problem child," contributing in large part to the self fulfilling prophecy for failure for these children. Within the public service agencies, such as Welfare and Children's Services Division, there is a great need for further education of professionals about the needs of the child with epilepsy.

These children and their parents need an advocate to permit successful community integration of these children. Often, the family needs a counselor or "coach" to assist in the day to day behavior management problems. The behavior management problems of the child with epilepsy are not unique. They are, in

most cases, the same problems experienced by other children. This fact, however, is not well known and many families with epileptic children do not develop effective strategies for successful living, because they are overwhelmed by the child's illness.

Against the background of these needs, the Clinic was established at Good Samaritan. The primary purpose of the Clinic was to survey the needs of the child with epilepsy and to provide information to the community, both schools and social services agencies, which would permit more effective management of these children. We learned that few community resources existed for these children, many of whom were placed in the Homebound Education programs because of their uncontrolled seizures. Placement in the Homebound Education program provides the child with five hours of instruction per week, but further compounds the isolation and frustration of the child who is removed from his peer group. The anxiety of the family is markedly increased under these circumstances.

"Family" problems, which are vaguely recognized, are often too complex for the busy treating physician to manage. Although school administrators and teachers wish to provide better service for these children, there is no effective program or strategy to maintain these children in the mainstream of education. The individual child with epilepsy has no special advocate. He has no place to demonstrate his ability to function effectively and prove his capability to learn to participate in the work of childhood. Finally, the special problems of a chronically handicapped child place a heavy burden on parents, who often search in vain for answers to their child's special problem and for strategies with which they can deal with the challenges that their child presents to them.

With these observations, the Clinic began to reassess its role as a diagnostic and evaluation center. In 1971, the Clinic altered its program, so that each child is examined by a multidisciplinary team. The team members include the following: a. child neurologist, b. child psychologist, c. preschool and elementary school teacher, d. social worker, e. other specialists required for complete evaluation of the child. These work-ups are conducted at the Clinic. At the completion of each work-up, a detailed staffing is held. The referring agency or physician is invited to these staffings. Plans for the child's future are proposed with the feedback from the referring agency, and a follow-up plan is defined.

The Clinic established its first educational classroom program for children with epilepsy in 1971, which began with one teacher in a classroom on the hospital campus. The goal was to determine the ultimate feasibility of returning these children to their own classrooms. The Clinic teacher served as an effective advocate for the child in his placement in a regular school environment. The initial funding for this program came from several sources. Developmental Disabilities Services Administration provided part of the funds. Multnomah County Mental Health Department provided additional funds. Good Samaritan Hospital provided a place for the program, as well as administrative and morale support. Subsequently, considerable assistance was obtained from Portland Public Schools.

In 1972, a second classroom was added, a "preschool" for children with epilepsy. In addition to the preschool, a parent education and training program was initiated, carefully planned and managed by three graduate students in social work as the subject for their masters thesis practicum. It was apparent that the preschool program was serving a large, unmet need and that a second preschool would soon be necessary. So in 1973, a second preschool was added. Portland Public Schools provided the salary of the third teacher and supervisory support for the entire program. There are now two preschool programs, the first of which deals with children from birth to age three. The second program deals with children age three to age six. The elementary school program deals with children age six to twelve.

In 1974, the Clinic was significantly expanded. Over 200 children per year are being evaluated by the Clinic. The current preschool enrollment is 28 students. A part-time physical therapist provides support to the preschool program. Social work and psychological services are also being provided for the preschool and elementary school programs.

The elementary school program, which was begun as an on-campus classroom for children who had been previously in the Homebound Education program, has significantly changed its role. Funded in part, initially, by the Homebound Education program in the State of Oregon, the role of the elemen-

tary school teacher has changed in the past year. The teacher now serves as the child's advocate. In many cases, the teacher works to maintain the child in his present regular classroom placement rather than assisting in the implementation of a program for the child outside of his own school. This is an effective means of increasing teacher awareness of the needs of the child with epilepsy within the child's actual school environment. The program has been very well received by the community and will undoubtedly be expanded in the coming year. It is anticipated that an on-campus classroom will be maintained at Good Samaritan Hospital in order to permit the development of EEG Telemetry techniques and more intense medical management in select cases.

1974-75 will see the development of an expanded parent education and training program with the addition of a full-time psychologist, who will work primarily in developing effective behavior management strategies. He will also serve the child as a community advocate in order to prevent the social isolation and low self-esteem which has characterized the development of the child with epilepsy in the past.

Currently, the program is funded, in part, by a grant from Social Rehabilitation Services. The original expansion of the Clinic was made possible by a Developmental Disabilities grant during the first two years. With the Social Rehabilitation Services grant, the Clinic's community role is greatly expanded and the community interest in the Clinic has grown markedly. The Good Samaritan Hospital and Medical Center has provided the Clinic's physical location without cost. The many "fringe benefits" of association with a large, progressive medical center are too numerous to list but should be duly recognized. In 1973, the Women's Auxiliary of Good Samaritan Hospital raised \$10,000 for the Clinic with a "Pops Concert." Several very generous gifts and bequests have been obtained for the Clinic through the efforts of Good Samaritan Hospital.

With County funds and private donations, the Clinic is able to operate a sliding fee scale, making the Clinic accessible for all patients, regardless of the patient's capability.

The utilization of public and private money in this program has allowed the Clinic to spend nearly all of its annual budget in patient services. Each of the Classroom teachers collect data on the progress of the children who are in the classroom. In a recent survey of the programs which were funded initially by Developmental Disabilities grants, Good Samaritan Hospital performance data collection, and accountability received very favorable mention.

Currently, the educational program at the Clinic is supervised by Portland Public Schools. All of the teachers are at the masters level and are extraordinarily well qualified for their positions. Although the Clinic has been funded to provide services for children with epilepsy, it is prepared to serve all neurologically handicapped children. The staff is well versed in the needs of the child with cerebral palsy and developmental retardation and other neurological problems.

Much remains to be done. The Clinic is small. The numbers of children seen is small and a long waiting list is developing. It is apparent that other clinics are needed, not only in Portland, but throughout the state and the nation. There are many needs which have not yet been addressed. For instance, the teenager with epilepsy is a forgotten individual. These children have special needs related to their vocational training and ultimate job placement. It is not a coincidence that the major concern of these individuals with epilepsy as defined by the Epilepsy Foundation of America, is related to jobs.

The emotional disturbed child with epilepsy in need of a group home or residential treatment center is a largely unmet challenge. These residential treatment centers should be in the child's community. Many of these children have severe problems, with which the families are unable to deal effectively. These children do not have advocates and unfortunately, the community tends to ignore these children or to implement stop-gap measures for their "containment."

The state and local agency personnel must be educated about the needs of the child and adult with epilepsy. We have found that personnel in these agencies, such as the Children's Services Division and Welfare Department, are eager to learn more about the needs of these individuals. However, there is no concerted program to provide them with the information with which to make administrative and service decisions.

The special needs of the child with epilepsy can and must be dealt with effectively if these individuals are to reach adulthood successfully. There are many

avenues of help for these children which are not being explored adequately. New ways must be found to remedy this situation. In working with its population of children with epilepsy and related problems, the Clinic has barely touched the surface of a deeper underlying problem in terms of the large number of children who are not being served. In the ultimate development of the individual with epilepsy, any limitation of that individual's vocational potential or dependence of that individual on public assistance programs represents a significant financial loss to the community. It is my feeling that such a program can demonstrate and does demonstrate an effective multidisciplinary way to prevent this loss to the community. More importantly, the intangible "loss of self-esteem" and "limited potential" represent the ultimate challenge.

Thank you for the privilege of appearing before you. The interest you have displayed in the cause of epilepsy is welcomed and I pray for your success in this endeavor.

#### CLINIC FOR NEUROLOGICALLY IMPAIRED CHILDREN

##### GOOD SAMARITAN HOSPITAL AND MEDICAL CENTER

#### Initiation

The Clinic for Neurologically Impaired Children was initiated in 1963 by Dr. Robert S. Dow, currently head of the Department of Neurology at Good Samaritan Hospital and Medical Center. At that time, the Clinic utilized a team of consultants and functioned only as a testing and diagnostic service to the community. Dr. James R. Schimschock accepted leadership responsibilities for the Clinic in 1970.

Dr. Schimschock, with the support of the Portland Public Schools, initiated the first therapeutic classroom in 1971 in the hope of providing academic intervention to the high number of school-age children with diagnosed severe seizure disorders. These students were receiving no more than four hours of academic instruction per week in the "Homebound Program". By midyear the waiting list for placement into this "special classroom" was well established.

In the Fall of 1972, Dr. Schimschock initiated the first preschool program in the nation for neurologically impaired children. The Monday diagnostic service continued and the School-Age Classroom remained in operation.

The Clinic operation was again revised in 1973 to meet an expressed community need. The waiting list for the therapeutic classrooms was long. As a result, another preschool classroom was initiated to meet the needs of those children between the ages of birth and three years in 1973.

Through continued support by Good Samaritan Hospital, Multnomah County Mental Health Division, Social Rehabilitation Services Administration, and the Portland Public School District, the Clinic is currently operating a two phase program:

(1) Mondays are reserved for the diagnostic team to evaluate over 200 children with suspected neurological impairments per year from all over the state of Oregon.

(2) Tuesday through Friday the three therapeutic classrooms are in operation providing academic intervention to over 40 children per year with diagnosed neurological impairments.

The *Infant Stimulation Program* sees children birth to three years.

The *Preschool Program* sees children three to six years.

The *School-Age Program* sees children six to twelve years.

#### Purposes

(1) Early accurate diagnosis of neurological impairments.

(2) Maintain a team of consultants for diagnostic evaluations, to support the therapeutic classrooms, and to deal with family and patient problem areas.

(3) Academic intervention as early as possible for neurologically impaired children through operation of three therapeutic classrooms.

(4) Placement of patient and family into appropriate community resources. Follow along service.

#### Funding

(1) From 1963 to 1969 the Clinic had a variety of funding sources, none of which remained for over a one year period.

(2) In 1969 the Clinic attempted to be self-supporting and failed due to the large percentage of indigent patients financially unable to pay for needed services.

(3) In 1970 the State Mental Health Division funded the Clinic for \$5,000 toward a needed \$30,000 budget.

(a) State Developmental Disabilities Services Act funded the Clinic in 1971 for \$12,500. This grant allowed the Clinic to activate a diagnostic program with limited services.

(b) Portland Public School District provided the salary for the initiation of the School-Age Classroom in the Fall of 1971.

In 1972, the State Development Disabilities Services Council granted \$23,000 to the Clinic. This money allowed for expansion of diagnostic services and helped to diminish the long waiting list of those patients to be seen in the diagnostic clinic.

The Social Rehabilitation Service Administration (Federal money) granted \$39,665 to the Clinic in March of 1973. This funding was renewable for three years at level status.

Social Rehabilitation Services Administration renewed Clinic grant in March of 1974 at the rate of \$54,074 for expansion of Clinic operations in the area of consultant time.

#### CURRENT CLINIC BUDGET

	Time percentage	Funding
<b>Service:</b>		
Project director.....	20	\$6,400
Administrative coordinator.....	100	8,436
Infant stimulation educator.....	100	9,330
School age educator.....	100	9,820
Medical social worker.....	20	2,016
Clinical psychologists (2 psychologists, 25 percent each).....	50	9,560
Equipment.....		500
Supplies.....		2,500
Travel.....		1,000
Other.....		1,000
Parent education—Child management program.....		3,512
<b>Total SRSA funding.....</b>		<b>54,074</b>
<b>Additional funding:</b>		
Multnomah County mental health division (coverage of indigent patients).....		5,500
Portland public school district (preschool educator's salary).....		12,249
Good Samaritan Hospital (in-kind donation of facility and services).....		7,000
<b>Total clinic functioning budget for 1974.....</b>		<b>78,823</b>

#### CLINIC CHILDREN DIAGNOSED—CHILDREN PLACED IN CLINIC CLASSROOMS

	Sept. 1, 1970 to June 30, 1971	July 1, 1971 to June 30, 1972	July 1, 1972 to June 30, 1973	July 1, 1973 to June 30, 1974
<b>Statistics:</b>				
Children evaluated in diagnostic clinic.....	45	110	141	210
Children placed in schoolage program.....		19	7	11
Children placed in preschool program.....			14	12
Children placed in infant stimulation program.....				16
<b>Total children seen in diagnostic clinic from Sept. 1, 1970 to present.....</b>				<b>506</b>
<b>Total children placed in therapeutic classrooms from July 1, 1971 to present.....</b>				<b>79</b>

It is important to note two important facts from the Clinic statistical information covering the time period of 9-1-70 through 6-30-74:

(1) Those children seen in the diagnostic clinic and not accepted into one of the three therapeutic classrooms are always provided placement in another academic setting which best fits their particular needs. Follow-up and placement are a guaranteed Clinic service.

(2) The statistics indicate a Clinic growth pattern in relation to the funding level of the Clinic at that particular time. As funding increased—the amount of Clinic services provided to the community also increased.

## FUTURE PLANS.—CURRENT CLINIC CONSULTANT TIME

[Amounts in percent]

	Presently	Future
<b>Consultant—</b>		
Project director.....	20	20
Administrative coordinator.....	100	100
Medical social worker.....	20	100
Clinical psychologists (2 each).....	25	50
Parent education—child management.....	1 20	20
Secretary.....	1 100	100

<sup>1</sup> Donated time.

(1) Present consultant time allows only 200 children to be seen per year. With a full time staff, over 400 patients could be evaluated with improved quality. This would double the current resources available to the community and diminish the two month backlog time which is the present waiting time before a patient can be evaluated.

(2) Family counseling, parent education, and the child management courses are presently volunteered by staff members. Each program is only twice per year for 8 weeks. The need is overwhelming for these vital services and an intense, structured program year-round is required. This expansion calls for additional staff members.

(3) Most importantly, the diagnostic clinic is always booked one to two months ahead due to vast community need. Additional staff time would eliminate this backlog of patients and allow for an even higher quality of service to the community.

Mr. KYROS. Thank you, Mrs. Belcher.

Would you say one of the single great test needs then in any local community in handling this problem would be to have a clinic like the one you described in Oregon?

Mrs. BELCHER. Yes, the one in Portland is both publicly and privately funded. It is a great help to the child and the community. State legislators, members of our city council have attended the clinic and are aware of it and when our government officials became aware of a thing in the community, they are more apt to work for better programs.

Mr. KYROS. Mr. Williams, what about Federal assistance in vocational rehabilitation for epileptics? Are there any specific funds earmarked? Should there be more help to States like yours and other States to develop programs?

Mr. WILLIAMS. The only way they will make funds available for us is that we have a multiple-handicapped workshop. Whenever we went to the multiple-handicapped workshop, the vocational counselors, because they found it easier to place the other disabilities, would refer other disabilities rather than the epileptic to our shop.

We went to the vocational rehabilitation several times to try to get funding for it and they said they had to get shops that could service all the vocational rehabilitation rather than for a specific disability.

Mr. KYROS. So Federal funds are earmarked for general disabilities rather than—

Mr. WILLIAMS. Right.

Mr. KYROS. They should not necessarily be separated out for epilepsy, should they?

Mr. WILLIAMS. I think they should be because when we are talking about vocational rehabilitation of the epileptics, we are not necessarily

talking about giving this person a skill as we might talk about some person who was injured, whereas he was restricted from activities he could gainfully do.

We are talking about first getting this person in a frame of mind that he can cope with his disability and accept it to the point where he could make himself acceptable as an employee. We are also talking about informing the potential employer as to what he should expect from this employee in a seizure phenomenon, so he would not feel uncomfortable in the instance of a seizure.

Mr. KYROS. You think under the circumstances rehabilitation and counseling for epileptics should be a unique kind of a specialty rather than putting it in with other problems.

Mr. WILLIAMS. True, and I think the counsellors themselves admit this is so because whenever any of the counsellors—and I know every counsellor in Los Angeles that has an epileptic on his caseload because they call me, "What should I do with him"—so the counsellors are not prepared. They don't know where to start.

If you have seen the book by Mr. Funk on the spectrum, it shows the varied kinds of information that is available. And I think EPIHAB has been the only place that has worked at trying to develop positive information for screening and placing epileptics in jobs.

Mr. KYROS. Thank you very much.

Mrs. Root, you told us this morning about your young daughter and the problems that she encountered in school, and the cruelty of young children in classes; even when they don't mean to be cruel, they are. Could you give us other examples of the prejudices you have experienced as a mother of an epileptic child?

Mrs. Root. I would like to point out when she first started school, her teachers were petrified of her and did not want to be around her. It was more or less a tossup after she got out of kindergarten as to who would get her in first grade. The parents of some of her peers were afraid for their children to be around her, because if she were to have a seizure, it would be a traumatic experience for their children.

My neighbor who has made an earnest effort to understand epilepsy after 4 years is still convinced, among others, that the child has brain damage and she does not have brain damage.

I would like to point out the Girl Scout incident to emphasize the ostracization, the prevention of keeping me from being a Girl Scout leader, which just happened several weeks ago. But this was not from the Girl Scout organization itself, but from a group of mothers who did not know me personally, but who were coordinating and decided since I had a child who had epilepsy, that it was definitely assured I would prevent all the other girls in the Girl Scout troop from functioning normally.

I would like to point out the only thing my child cannot do is go horseback riding and go swimming alone. These are some of the many cases.

Mr. KYROS. Those are subtle, too. Those would not normally be apparent. I can understand the schoolchildren, but I don't think the others would come easily to mind. You almost have to have that unique experience yourself.

Martha, have you ever encountered any legal problems because of epilepsy?

Miss MITTENDORF. Because I have epilepsy, I cannot obtain a driver's license at this time. This has been a problem because of my age group partially and I like to move around and be able to move around on my own a little better.

Mr. KYROS. What did they tell you when you tried to get a driver's license?

Miss MITTENDORF. My neurologist said, "I don't think you will ever be able to get one because you will have epilepsy all your life." But what I have heard is that if you don't have seizures for a period of 2 years or grand mal seizures, then there is a way of obtaining a driver's license. And I did not know this before.

Mr. KYROS. So you would have to have a period when you did not have seizures for 2 years or so?

Miss MITTENDORF. That is what I heard, but I am not sure if that is right or not.

Mr. KYROS. I certainly want to thank everyone on the panel, and again I think you have done a single public service to have come here and tell us of your private grief and I think it is a good thing, but I think we should all share in it and try to do something about it. I think it is a message that certainly will not be wasted or lost on this committee.

Thank you all very much.

Before we proceed with the next witness, without objection, the Chair wishes to place in the record, as though read, a statement submitted by Representative Patsy T. Mink, of Hawaii.

#### STATEMENT OF HON. PATSY T. MINK, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF HAWAII

Mrs. MINK. Mr. Chairman, I commend the Subcommittee on Public Health and the Environment for its hearings today on H.R. 13405, Congressman Kyros' bill to establish a National Advisory Committee to develop a national plan for the control of epilepsy and its consequences.

Centuries of awareness of this disease and its manifestations have not brought understanding. Unlike cancer or heart disease which elicit large research contributions as well as compassionate concern for its victims, epilepsy remains under-researched and its victims actively discriminated against.

H.R. 13405 addresses itself to both these aspects of epilepsy; they are intrinsically related. So long as popular misconceptions about epilepsy continue to flourish, epilepsy will remain a fearful and yet avoided subject. Ignorance will continue to exact a bitter social and psychological toll from epileptics already struggling to cope with the physical demands of their disorder. Ignorance and superstition will negate those very advances we make in research and treatment.

H.R. 13405 recognizes that a massive infusion of money would redress only part of the problem. The pivotal factor is public awareness. Congressman Kyros' bill would afford responsible recognition to epilepsy and the multiple needs of epileptics. Through that recognition, it would give emphasis and impetus to epilepsy research.

Most importantly, however, it would provide coordination. Coordi-

nation is desperately needed to fight a disease whose physical implications are so intertwined with its social aspects.

The Federal financial commitment would be minimal and, I believe, the committee and its development of a substantive, coordinated, far-sighted national plan would accrue benefits far in excess of our investment.

For the sake of those 4 million Americans who suffer from epilepsy and whose fulfillment of their lives is so tragically constrained by our own ignorance, I urge your adoption of H.R. 13405. The time and circumstances cry out for a centripetal force—a program which can draw together disparate projects and research and provide a real measure of hope to epileptics. I believe H.R. 13405 offers such hope.

Mr. KYROS. Next I would like to place in the record a letter I received this morning from Senator Peter Dominick from Colorado. Senator Dominick is a prime sponsor of legislation similar to ours on the Senate side and I will put the entire letter in the record.

He also lays forth how important it is to develop a national program for epilepsy and his attempts on the Senate side to pass a similar bill. So we will make this a part of the record at this time.

[Letter follows:]

U. S. SENATE,  
Washington, D.C., August 9, 1974.

HON. PETER N. KYROS,  
U.S. House of Representatives, Washington, D.C.

DEAR PETER: I wanted to take this opportunity to let you know that the press of other business prevents me from joining your hearings on Monday, August 12th. I will, however, be following them closely, and hope that meaningful data will be developed concerning this most serious medical problem so that we can move forward in developing a national program for epilepsy.

The importance of the need for focusing attention on this problem, I believe, is reflected in the fact that your proposal is cosponsored by all of the members of the Health Subcommittee. In addition, as you know, S.J. Res. 173, calling for the establishment of a similar Commission on Epilepsy is now cosponsored by 14 other Senators, and I now expect that Senate action will occur on the basic provisions of my bill in the near future.

As I noted upon introduction of my Resolution: Epilepsy is indeed a major national health problem—both in terms of cost and suffering. It touches the lives of more than four million Americans at the present time, and thousands of additional cases arise each year as the result of head trauma alone. The total cost to society from this debilitating neurological disorder is estimated at \$7 billion annually.

Epilepsy strikes all age groups, but particularly the young. For example, more than 670,000 elementary school children and more than 300,000 secondary pupils are afflicted with epilepsy. If left untreated, it creates severe learning barriers, deters social development, and prevents its victims from achieving self-sufficiency. With proper treatment, epilepsy can usually be controlled and its victims can live productive lives—providing they are among the lucky ones with access to adequate treatment and the resources to pay for it.

If epilepsy were contagious, perhaps a Jonas Salk would have attacked it. National attention and resources would have been focused on the problem of stopping an epidemic of such magnitude. But epilepsy is not contagious, and it is usually not fatal. Nevertheless, it is extremely destructive.

The focusing of national attention on the problem of epilepsy is long overdue, and I hope the Subcommittee's hearings shall be productive.

Best personal regards.

Sincerely,

PETER H. DOMINICK,  
U.S. Senator.

Mr. KYROS. Our next witness will be Dr. John Van Pelt from the Maine Coast Memorial Hospital, Bangor, Maine.

Dr. Van Pelt, I certainly want to welcome you to the committee. Dr. Van Pelt is from my State of Maine. He is a pediatrician and he is also chief, medical services, Elizabeth Levison Development Center. He also serves as president of a statewide epilepsy organization in Maine which devotes itself to alleviating the problems of the disorder in that State.

May I especially welcome you, Doctor, first as fellow citizen of Maine and, second, as a man particularly dedicated to children's health. You may be aware of my personal involvement in the case of a young Maine child, Josh Lea. Last winter I was able to help his family obtain a supply of a drug called Mogodon, which brought his rare form of epilepsy under near-miraculous control.

The child had been experiencing as many as 70 seizures every 8 hours and with the administration of the drug under their family doctor's care, the seizures dropped to nearly zero. So now I have a deep, personal appreciation of how satisfying it must be to those of you with daily work toward the control of this problem.

Dr. Van Pelt, we will be interested in hearing your remarks not only with regard to the medical problems of epilepsy, but also with regard to the problems of setting up State organizations to get a wide variety of services to those who need them.

**STATEMENT OF JOHN VAN PELT, M.D., ATTENDING PEDIATRICIAN,  
MAINE COAST MEMORIAL HOSPITAL, AND CHIEF, MEDICAL  
SERVICES, ELIZABETH LEVISON DEVELOPMENT CENTER**

Dr. VAN PELT. Thank you, Mr. Congressman. It is a great pleasure to be here and to share with you for a brief period of time some of the problems that you may be well aware of with this particular effort in Maine and many of which perhaps are unfamiliar.

I have a prepared statement which I would ask to be included in the proceedings of the record, so if I may very briefly, perhaps mercifully briefly, wander a bit from the written score.

I think what is going on in Maine, or perhaps what has not gone on in Maine as regards the effort to help those with epilepsy, maybe represents a microcosm of what is happening elsewhere in the Nation. Whether it is worse in Maine or not, I cannot say. I can tell you something of the problems we have there and I think I can sum it up by saying we need help and we need it very badly.

You alluded a moment ago to the fact that we have been trying to start a lay organization, a chapter of the Epilepsy Foundation. The initial response to this effort was good and there was a lot of enthusiasm; and then a curious thing happened. Since I am not myself epileptic, it took me a while to understand this. Many of the people who theoretically should have benefitted from this effort, and who initially endorsed it enthusiastically, shied away from association with the group because of the threat to them, which is a real one, of public disclosure because of their involvement with the then fledgling organization.

Really, I think one can say at this time in terms of trying to establish a chapter in the State, it is going to happen because of the necessity for the Development Disabilities Council to become involved with

some epilepsy effort, but actually without that necessity, I think it would be a long time coming to the State.

Beyond that there is hardly any service for an epileptic, either medical, social, rehab, educational, or what you will, that we could not use more of, better of, and better coordination of, within the State. It is a tremendous task, even in a small State with 1 million people, to begin to try to pull these ends together into some sort of unified program.

I believe the legislation you have proposed is probably the best hope that I have seen at any time in my 5 years of practice in Ellsworth to begin to have some unified approach to the problems that we have there, and I very much hope that, with this beginning, we can begin to see some really substantial inroads into the many problems that epileptics in Maine have.

I think that is what I had to say. I promised to be brief, so I have been.

[Dr. Van Pelt's prepared statement follows:]

STATEMENT OF JOHN VAN PELT, M.D., ATTENDING PEDIATRICIAN, MAINE COAST MEMORIAL HOSPITAL, AND CHIEF, MEDICAL SERVICES, ELIZABETH LEVISON DEVELOPMENT CENTER

#### EPILEPSY IN MAINE

##### *Introduction*

I am Dr. John Van Pelt, Attending Pediatrician, Main Coast Memorial Hospital and Chief of Medical Services, Elizabeth Levison Development Center. I am honored to testify on behalf of the Kyros Bill calling for a National Advisory Commission on Epilepsy.

As you no doubt know the State of Maine has a population of approximately one million. Actuarial figures based on the statistics suggest that there are around 20,000 people affected by epilepsy in the state. How do they fare?

To begin, there is presently no way to determine whether Maine has 20,000 epileptics or 5,000 or 30,000. For many reasons, the few attempts that have been made to assess the size of the problem have lacked comprehensiveness and the numbers therefore, may be inaccurate. Maine is a rural state with a widely scattered population and diagnostic and treatment facilities are uncommon, and the varieties of medical experts qualified to treat seizure disorders, rare. A medically unsophisticated population, often with limited financial resources, creates a milieu in which people may have epilepsy without knowing it, while others know it, but are afraid to admit it; finally those that have epilepsy and are not afraid to say so are treated to the fears, prejudices and misconceptions of the small town, where epilepsy is often equated with mental sub-normality or mental illness. There is much to be done.

##### *Problems*

##### *A. Education*

Maine is 46th of the 50 states in per capita expenditure for education. While spending more money per student in no way guarantees educational quality, this statistic suggests that the range of educational experience available to the student, and the depth of educational services available to those who need them, are less than might be available in the 45 other states. Limited educational opportunities tend to perpetuate ignorance, and ignorance is the natural enemy of the epileptic. Unless the accumulated myths and prejudices of generations are dispelled by appropriate educational means, the epileptic individual is destined to encounter the same barriers forever. Such is the situation in Maine where, for example, the average classroom teacher or school principal knows little or nothing about epilepsy or the epileptic child and fears the label nearly as much as the bubonic plague. Public education about the epilepsies is one of the most urgent immediate needs for the epileptic in Maine. At present, there is almost no activity in this area in the state.

### *B. Medical*

Most of the sorts of diagnostic and treatment facilities that might be considered requisite for management of seizure patients are located in the southern end of the state. The only seizure clinic is in Portland. There are a total of ten neurosurgeons and seven neurologists (and no pediatric neurologists) in the state, all of whom are practicing in the southern half. The patient-to-physician ratio is well below the national average of approximately 1,000 to 1. But the Maine figure includes areas and entire counties where the ratio is more like 3,000 to 1. There are many conscientious and well trained physicians in Maine, but very few with specific training and/or interest in the epilepsies. A dearth of facilities, wide geographic distances, and an occasionally harsh climate make it extremely difficult for the epileptic to receive minimal care, let alone adequate care.

### *C. Vocational*

It is also extremely difficult for epileptic individuals to obtain stable employment in Maine. Many employers simply will not hire people with seizures, no matter how well qualified for the job and no matter how well controlled the seizures. It has done no good, in my experience, to bring these cases to consumer action groups, human resources counselors, the Fair Employment Practice Commission and the like. As an example, a 20-year old woman, a high school graduate, was explicitly refused employment as a check-out counter operator in a large department store in the Bangor area. This went to a consumer action group by the name of COMBAT that was able to accomplish nothing for her.

In many of the smaller cities there may be only one major employer, and if that company has a personnel policy which excludes the epileptic, then the individual either lies about his illness and takes his chances of being found out or moves elsewhere. I know of a brother and sister with epilepsy in a town called Dover-Foxcross in the northern part of the state. The brother was totally unable to obtain employment in his home area, no one would employ him, even though his seizures were well controlled. His sister got married and got around the problem that way. But he eventually was forced to move to Virginia where he obtained rehabilitation services, job training, and steady employment, all of which he was unable to get in Maine. Those epileptics who do hold employment in company towns in Maine are frightened for their jobs should their medical history be known.

Until fairly recently, the vocational rehabilitation facilities of the state were reluctant to accept candidates with seizure disorders. Happily, the situation has changed, but the rehabilitation people have the same difficulty obtaining capable medical service as the rest of the state does.

### *D. Public Action*

Four years ago a group of concerned individuals in the Bangor area began to establish a local lay organization for the purpose of group support and public education. Initially, the results were encouraging with good reception by the effected individuals and we obtained a glimpse of the size of the problem and concerns of the patients through the mail. But the effort became bogged down, partially because of lack of funds and problems within the group. This was attributable to the fear of public disclosure that association with this group might afford, and this was too threatening for many.

### *Summary*

In answer to a question asked in the introduction (How does the epileptic in Maine fare?), it would appear that the epileptic in Maine is not faring very well, for the reasons detailed. It is clear that many of the current difficulties could be attacked by a program that sought:

1. to provide aggressive public education;
2. to improve medical services for the epileptic;
3. to take an aggressive stance on the employment rights of the individual with epilepsy.

It is my opinion that the legislation proposed by Congressman Kyros will create exactly the mechanisms needed to get a substantive effort launched, once and for all, not only in Maine, but all across the Nation.

Mr. KYROS. So one of the problems is public education, because whether it is a driver's license or employment or schools, apparently people attach significance to epilepsy that just does not exist; is that right?

Dr. VAN PELT. Indeed; you have heard allusions, I am sure, this morning and this afternoon to the stigma of the diagnosis. This has many, many sides to it and it can be very abrupt and vicious and it can be very subtle, but in order to obtain a license to operate a motor vehicle in Maine you have to be certified as being suitable for this honor by a neurologist and, he must say that you have been seizure free for at least a year.

Mr. KYROS. Is that the law in the State of Maine?

Dr. VAN PELT. Mr. Congressman, I am not sure if that is the law or if it is an unwritten law, but I am one of the inspectors for the State and that has been the word of mouth regulation.

Mr. KYROS. Do doctors, physicians themselves, do they require some kind of specialty training to recognize and diagnose epilepsy and treat it?

Dr. VAN PELT. Here is a perplexing thing for the consumer. If someone is listed in the Yellow Pages of the phone book as being a neurologist, he therefore should be qualified to diagnose and treat seizure disorders. In point of fact that may be the case, but it may be that he is a practitioner that has little or no interest into the management of seizure disorders and problems of epileptics.

I know two colleagues who are fine neurologists, well-trained at an eastern medical center, who neither one have much interest in epilepsies. They refuse to use the term in diagnostic terminology with their patients, it being a term that is too stigmatizing. As a consequence, I think, they are very often doing more harm in dealing with an epileptic than a good family doctor, who may not have as much formal training, but can emphasize with him to a greater extent.

Mr. KYROS. If we rely solely on private groups like the Epilepsy Foundation of America, in rural areas can you get groups established and funded to do something about training, education, treatment, diagnosis, or is it very difficult?

Dr. VAN PELT. As you know, Maine has no medical school so there is a real problem with innovating medical services. There is not a medical community that is pushing to develop this sort of thing like my colleagues at this table have been pushing in other parts of the country.

I think it would be quite within the realm of possibility that one could get a lay organization for public education off the ground, as for example a chapter of the Epilepsy Foundation.

That consumer organization might eventually, with a lot of pushing and shoving and digging and clawing, achieve some improvement in the medical facilities available.

I think that is a very good way of making things happen, but it takes an awfully long time and I think this is one of the most discouraging things for the epileptic, the timespan. He knows things should be happening, things could be happening.

If he goes to another State, things will happen. It is awfully hard to be patient.

Mr. KYROS. You are a pediatrician? Is that your specialty?

Dr. VAN PELT. That's right.

Mr. KYROS. What are the major problems that you face with young epileptics?

Dr. VAN PELT. I think you heard some of them from the consumer panel. They are more related to the social aspects of epilepsy than they are to the medical. That is not always the case, of course, but by and large in terms of the day-to-day operation of a pediatric practice which has a fair number of epileptic children in it—I have a harder time dealing with the social and academic difficulties of the youngsters than I have with the strictly medical aspect of managing their seizures, especially when they get into the high school age bracket and they want driver's licenses or their families want them to be insured or they want to take up a profession or go scuba-diving or whatever, and you tell a kid who is 16 that he or she cannot do that, or they cannot be certified to do that or they cannot get this, that or the other thing, they want very badly—as you may remember from your own adolescence, that only makes the adolescent want it more and the result is a lot of emotional unrest and it is difficult to resolve this.

It takes a great deal of counseling and it takes a great deal of time. I spend Tuesday evenings in my office basically counseling these people. That is what I devote that section of my practice to and I am only touching the very tip of the iceberg and the people that are immediately adjacent to Hancock County.

I don't know what happens elsewhere in the State. I have not the remotest idea. I know the vocational rehab people have not been very receptive to the needs and difficulties that these young people have.

Mr. KYROS. Thank you very much, Dr. Van Pelt.

Mr. Symington, do you have any questions?

Mr. SYMINGTON. Not at this time. Thank you very much.

Mr. KYROS. Thank you very much and we appreciate your coming here. I understand you are on the subsequent panel, so you can remain here for a moment.

At this point we would like to continue with the panel format in order to obtain the widest possible views of the problems and needs faced by people with epilepsy and those who work in the field.

Our first panel this afternoon is made up of a distinguished group of medical men. The chairman of the panel is Dr. Adolph L. Sahs. Dr. Sahs has served as president of the American Academy of Neurology, as director of the American Board of Psychiatry and Neurology, and as Chairman of the Neurology Study Section of the U.S. Public Health Service. He is also a counsel for the American Neurological Association.

Dr. B. Joe Wilder is chief of neurological services at the VA hospital in Gainesville, Fla. He is also professor of neurology at the University of Florida and director of the epilepsy laboratory at the University of Florida Medical Center.

Sitting on the panel with Dr. Sahs and Dr. Wilder will be Drs. Daly and Van Pelt.

Gentlemen, welcome to the committee.

# STATEMENTS OF A MEDICAL PANEL:

**ADOLPH L. SAHS, M.D., PROFESSOR EMERITUS, AND FORMER CHAIRMAN, DEPARTMENT OF NEUROLOGY, UNIVERSITY OF IOWA COLLEGE OF MEDICINE**

**B. JOE WILDER, M.D., CHIEF, NEUROLOGICAL SERVICES, VETERANS HOSPITAL, GAINESVILLE, FLA., PROFESSOR OF NEUROLOGY, UNIVERSITY OF FLORIDA, AND DIRECTOR, EPILEPSY RESEARCH LABORATORY, UNIVERSITY OF FLORIDA MEDICAL CENTER**

**DAVID D. DALY, M.D., Ph. D., PRESIDENT, INTERNATIONAL LEAGUE AGAINST EPILEPSY**

**JOHN VAN PELT, M.D., ATTENDING PEDIATRICIAN, MAINE COAST MEMORIAL HOSPITAL, AND CHIEF, MEDICAL SERVICES, ELIZABETH LEVISON DEVELOPMENT CENTER**

Dr. SAHS. Thank you, Mr. Chairman.

I will make my remarks very brief. I have a prepared statement which I will submit.

Mr. KYROS. And your statement will be made a part of the record, Dr. Sahs.

Dr. SAHS. As emphasized by the 1972 manpower report of the President, there is a dynamic growth in the demand for health care services in the United States and, consequently, a growing demand for health care professionals. Unfortunately, training seems to be an area that is in rather poor repute at this time and sufficient emphasis in my opinion has not been devoted to the training area.

So far as the demand is concerned, there are many factors which have contributed to this demand, including population growth, rising standards of living, and heightened health consciousness. But I feel that this demand is not being set fully in such areas as the training of physicians generally and in the specialties, the social workers, nurses, educators, hospital administrators, and others.

And it is in an area like this where I feel that definite support can come from a bill such as is being considered at this time.

Therefore, I would like to express my gratitude for having the opportunity to give this testimony in behalf of a significant effort to improve the lives of several millions of Americans.

Thank you.

[Dr. Sahs' prepared statement follows:]

**STATEMENT OF ADOLPH L. SAHS, M.D. PROFESSOR EMERITUS AND FORMER CHAIRMAN, DEPARTMENT OF NEUROLOGY, UNIVERSITY OF IOWA COLLEGE OF MEDICINE**

Mr. Chairman and members of the Subcommittee. I welcome the opportunity to appear today to testify on this proposed legislation to establish a National Commission on the Epilepsies. I am Dr. Adolph L. Sahs, M.D., Professor Emeritus and former Head of the Department of Neurology at the University of Iowa College of Medicine. I have been a past president of the American Academy of Neurology and a past president and Councilor of the American Neurological Association. I have also served as Chairman of the Neurology Study Section of the U.S. Public Health Service and am a past Director of the American Board of Psychiatry and Neurology.

Those who spoke this morning have illuminated the range and complexity of the problems associated with the epilepsies. As we might expect therefore, the kinds of health professionals with a specific interest in the epilepsies are also varied. To sketch briefly some of the dimensions of this problem we can consider just some of the medical and paramedical professionals involved; for example, general practitioners, pediatricians, internists, neurologists, neurosurgeons, electroencephalographic technologists, clinical laboratory scientists and laboratory technicians.

As emphasized by the 1972 *Manpower Report of the President*, there is a dynamic growth in the demand for health care services in the United States and consequently, a growing demand for health care professionals. There are many factors contributing to this demand, including population growth, rising standards of living and heightened health consciousness. Several factors make the projection of supply and demand of medical and allied health manpower somewhat difficult. For example, to predict choice of specialty, geographic distribution, effect of changing division of labor as increase demands on physicians' time necessitate increased training of other health workers.

How will these factors affect the delivery of health care to persons with the epilepsies? What plans are necessary in order to eliminate waste, misuse, and lack of preparedness? If we are to be prepared to deal effectively with the epilepsies, national planning should be undertaken as soon as possible, for we have no idea presently of the duplication of effort and waste in terms of training and manpower, let alone real future needs.

Determining the medical needs of the epilepsy population is further hampered by the lack of precise epidemiological data. It is impossible to plan in any meaningful way for the variety of services, treatments, facilities, manpower and research priorities without more specific epidemiological data. This has never been done on the scale and with the unity of purpose necessary to develop sound national planning.<sup>1</sup>

Only with an organized national thrust in this critical area can further meaningful progress in the control of epilepsy and its consequences be achieved. A National Commission is vital in carrying out this objective as can be demonstrated by the problems which have plagued all previous, but limited epidemiological studies. For example in surveys of physicians, reluctance has been encountered to "label" patients as epileptics while on the other hand, in pool-type surveys of population groups, reluctance has been encountered to admit the presence of the disorder. Such other factors as borderline diagnosis, duplication of records, and discrepancies within the medical community over diagnostic definition further impede data collection.

Another area in which sound planning needs greater emphasis is in basic medical research. This is so even with the fine accomplishments of the National Institute of Neurological Diseases and Stroke. Since its inception, the Institute has maintained a consistent research effort in the area of epilepsy and is to be commended for the progress it has made in advancing knowledge in the face of inadequate funds.

While basic research has given a deeper understanding of the ways in which nerve cells in the brain become epileptic, major questions remain unanswered. Further research is still needed in order that more effective treatments can be found. For example, the need for a new antiepileptic drug continues and while the National Institute of Neurological Diseases and Stroke is in pursuit of these goals, much more needs to be done. As you are aware, the funds for research in epilepsy have been rather small. Last year the total funds devoted to research in epilepsy from all sources was \$5 million and \$33 million of this expenditure was made through NINDS. Translated into practical terms, this means that the expenditure for research on patients with epilepsy amounted to \$1 per patient per year! Certainly our research efforts need to be expanded in order to coordinate these efforts effectively.

Others have testified eloquently this morning on the need for a comprehensive care program for the epilepsies, not only to provide better health care delivery, but to attack as well the whole gamut of educational, occupational, and social

<sup>1</sup> These problems have been illuminated in detail at a recent Workshop on Epidemiology. The proceedings are published in NINDS Monograph #14, U.S. Department of Health, Education, and Welfare, 1972, Washington, D.C.

problems faced by those with this neurological disorder. What is the best approach at this time? The answer to this question will most significantly affect the efficacy of efforts and planning in each of the many problem areas we have discussed thus far today. The most effective planning must take these other factors into account and this would obviously be a question best addressed by a National Commission with but one focus—the control of epilepsy.

Epidemiology, research expansion and priorities, and comprehensive programs are only three of the aspects of the medical problems which individually need National Planning. However, these can also be used to illustrate the necessity of a broader overview in planning than could be provided by any single agency currently in existence.

For example, where should Centers of Excellence be located throughout the country? How many are needed to provide maximal coverage at a minimal cost? How can research be most effectively expanded through these centers with the most benefit concomitantly to patients? What priorities in research can best be pursued at each Center? How should epidemiological studies be designed to be sure that prospective planning provides the data base for effective planning in these areas?

This same type of integrated planning approach is required for a whole host of other problem areas in the medical management of the epilepsies. Examples are, standardized diagnosis; training courses; seminars and workshops; outpatient services; standards for clinics; residential facilities; prevention; gas-liquid chromatography standards; and on and on. These various topics have been touched upon in the comments already made today and I know that Dr. Wilder will want to address those not already discussed. All of these are dramatic evidence of the urgent need for a National Commission and Plan.

In closing, I would like to emphasize that the progress we make in understanding and treating the epilepsies has broad significance for all the brain sciences.

Understanding the basic mechanisms of the epilepsies will mean understanding the basic mechanisms of the brain. We must proceed with all haste on this "royal road," as it has been termed, to understanding the brain while we alleviate the suffering of millions along the way.

Mr. Chairman, I would like to express my gratitude for being given the opportunity to testify before you today in behalf of this significant effort to improve the lives of millions of Americans.

Mr. KYROS. Thank you, Mr. Sabs.  
Dr. Wilder.

#### STATEMENT OF B. JOE WILDER, M.D.

Dr. WILDER. It is a pleasure and honor to testify before this committee. I have a written report that I request be made part of the permanent record.

Mr. KYROS. Without objection [see p. 90].

Dr. WILDER. I would like to restrict my remarks to some of the things that have been covered today already, No. 1 being research and development. We had a statement by the administration this morning that among the many achievements has been approval for the first time in 14 years of a drug for chronic use in epilepsy.

It seems to those of us in the medical field who actively are involved in diagnosis, treating and followup care of the epileptic patient that this is woefully inadequate. The last drugs being introduced in 1960, the most recent one being introduced this week.

We feel that the bill that is being considered will spotlight the need for the epileptic patient. The primary management of the epileptic patient is medical management through chronic administration of drugs.

We feel much more emphasis needs to be placed on drug research and development.

We heard of research moneys that have been spent, \$6.4 million. If we take the number of clients or the number of patients with epilepsy, this works out somewhere between \$1.50 to \$2 a patient, which seems, considering the magnitude of the problem that has been presented by many of the other panelists today, woefully inadequate.

In terms of seizure control, we were told that due to recent medical developments most patients enjoy relative freedom from seizures. In my experience and in the experience of my colleagues who work primarily with epileptic patients, this is not true. It would be my estimate that in general 40 percent of patients who are diagnosed as epileptics are receiving adequate treatment and are probably under good or excellent seizure control.

In centers where people specializing in handling epileptic patients have special tools available, then improvement can be increased to the 70 or 80 percent level. We feel that this level could be achieved with the currently available drugs in the majority of the epileptic population with such a national spotlight as your bill will put on the problems of the epileptic patient.

Age distribution was mentioned. Although epilepsy affects persons of all ages, the majority are children and young adults. I realize this has been referred to before this morning, however I would like to clarify this statement and say the peak incidents of onset of epilepsy is in the young child and adolescence. There is another peaking of incidence of epilepsy and that is in the older population, 55 to 65 years of age, because of a different ideology.

The best studies that are available indicate that somewhere between 50 percent and perhaps 60 percent of patients outgrow their seizures. However, I do not think that this is necessarily accurate because as people become older, they need to conceal the fact that they have epilepsy because of job opportunities and social situations.

I would suspect that the largest segment of epileptic patients taken on a number basis lies between 20 and 50 years of age.

We heard of new developments that have been made in the area of treating patients. Probably the most significant development was the introduction of the gas-liquid chromatography for rapid analysis of anticonvulsant blood levels. We now have methodology so that in a brief period of time we can determine the exact amount of the drug in the blood.

We feel we have fair guidelines as to what the concentration of drugs should be to effect maximum seizure control. We also know what levels to anticipate difficulties in terms of toxicity. This capability has been available for the past 4 or 5 years, yet at the present time I think it is safe to say that probably only 25 laboratories in the United States provide full service for all the anticonvulsant drugs on a service basis.

There may be 100 or so laboratories that periodically do drug analysis, but here is probably the greatest single breakthrough since the introduction of some of the major drugs. Yet we have not had utilization of this technique primarily because of failure for funds to develop laboratories, failure for dissemination information relevant to the value of this procedure.

Another thing is the standardization of these procedures. It is one of my worries and those of many of us who work in this area that it

may be worse for the treating physician to have incorrect blood levels than to have none at all. It is true the Bureau of Standards is developing standards. We would hope that legislation or a council report on epilepsy would recommend standardization of all laboratories that perform this service so that the physician who uses the service gets accurate information back.

Inheritance factors have been alluded to several times today. There is no doubt that a significant segment—by significant I would refer to certainly less than half—but a segment of the epileptic population has inheritance factors involved. I have a family I care for that has five children. All five children have focal epilepsy. All five children have similar electroencephalographic abnormalities. So here is a disorder with an inheritance factor, yet it is a focal type epilepsy which we do not usually regard as being genetically linked.

I think the passing of this bill will encourage overall recordkeeping, will encourage the exploration of the genetic factors involved.

Then last, I would make a comment on the availability of competent quality care. Competent quality care is certainly available in many centers about the United States. Perhaps over half of the epileptic population does not have quality competent care for diagnosis, treatment, and followup available.

I do not think this is an oversight of the medical profession, but it is more likely the lack of understanding of the problem and the failure to see the need.

In summary I support and urge positive consideration of the Kyros bill to establish a National Commission to develop a national plan for the epilepsies. The benefit sought would include an increased awareness of the problems and an investigation and evaluation of preventive measures, standardization of diagnostic procedures leading to adequate medical management of the epilepsies and, lastly, a net saving of money as duplication of efforts is reduced.

I might comment the taxes paid by the 1,500 people returned to useful occupations by Mr. Williams would support the Commission for a year.

Thank you very much, sir. It is a pleasure to have had this opportunity.

[Dr. Wilder's prepared statement follows:]

STATEMENT OF B. JOE WILDER, M.D., CHIEF, NEUROLOGICAL SERVICES, V.A. HOSPITAL, GAINESVILLE, FLA.: PROFESSOR OF NEUROLOGY, UNIVERSITY OF FLORIDA: AND DIRECTOR, EPILEPSY RESEARCH LABORATORY, UNIVERSITY OF FLORIDA MEDICAL CENTER

Gentlemen, I appreciate the opportunity to appear before this Committee to testify regarding the medical aspects of the need for a National Commission and Plan for the management of the epilepsies. I am Dr. B. Joe Wilder, Chief of Neurological Services at the V.A. Hospital in Gainesville, Florida, Professor of Neurology at the University of Florida and Director of the Epilepsy Research Laboratory at the University of Florida Medical Center.

At the heart of this problem is the fact that epilepsy is a disorder which is best approached as a symptom-complex because of the multiplicity of causes or etiological factors involved. This means that, although the presence of seizures is common from case to case, the underlying cause or causes may be quite different in each individual. It is the complex of presenting symptoms which allows for proper diagnosis and treatment of the whole medical problem faced by the patient with epilepsy. Therefore, as was pointed out earlier by others today, epilepsy is a multifaceted medical problem requiring a level of expertise in treatment not frequently found, especially in rural areas.

What are the alternatives in solving these problems of epilepsy? Is the distribution of adequate manpower the answer, or is the reorganization of already existing facilities needed? Perhaps increased and varied continuing medical education would be the remedy to this situation? These are crucial questions which would best and most efficiently be addressed by a National Commission. These kinds of answers are necessary especially at this time because many approaches have already been tried and now need to be evaluated, one against the other.

For example, in Florida we have recently developed guidelines for a Model Seizure Clinic which addresses itself to the long-term medical management of the epilepsies. Included in the guidelines are recommendations regarding staffing and personnel, facilities, and recommended agency affiliations. Florida, of course, has many rural areas and we therefore see some of the same problems as does Maine.

How does this approach compare with others? Does it have some of the answers for Maine? Now is the time to find out, and a National Commission in its role as an investigative and evaluative body would be the ideal catalyst for action.

I mentioned earlier the variety of etiological factors that could induce epilepsy. Let me give some examples. In the new-born, trauma associated with birth, anoxic episodes, infectious processes, inheritable disorders with primary alterations of brain metabolism are frequent causes of chronic recurrent seizures in early or late childhood. In the elderly, vascular or degenerative changes may result in focal or diffuse brain damage and epilepsy. Throughout life, central nervous system infections, vascular lesions, tumors and trauma can result in epilepsy. In some kinds of epilepsy, such as progressive myoclonic epilepsy, inheritance may be a factor. The list of possible causes also include drug abuse, alcoholism, high fevers, autoimmune disorders, sickle-cell disease, chronic leukemias, liver or kidney disorders.

This gentleman highlights another most important point—*anyone can be struck by epilepsy, at any time throughout their life and as a result of any one of a multiplicity of factors.* We are all susceptible.

This brings us to the question "How can epilepsy be prevented?" Every one of us, as potential epileptics, should be deeply concerned with this problem. Currently, efforts along these lines are scattered and fragmented. Let's take the example of post-traumatic epilepsy. As Chief of the Neurological Services of a V.A. Hospital, I am, of course, able to speak from firsthand knowledge of accidents resulting in epilepsy. However, it now appears that much of this suffering might have been avoided. Preliminary data suggests that prophylactic, anti-convulsant drug administration following significant head trauma can markedly reduce the subsequent occurrence of post traumatic epilepsy. Preventive prophylaxis could be as effective with many of the other causal factors which we discussed earlier. Once again the question must be asked, "How can current resources be brought to bear most effectively in approaching the problem of prevention of epilepsy?"

But even if we were to assume that we had enough knowledge to minimize the occurrence of preventable cases of epilepsy, we would still be relatively ineffective without a coordinated national effort. For without this type of planning we would still be faced with the problem of achieving nationwide application of the knowledge. This brings us full cycle back to the diagnostic problems we have already discussed.

In summary, I support and urge positive consideration of the Kyros Bill to establish a National Commission to develop a National Plan for the epilepsies. The benefits sought would include an increased awareness of the problems, an investigation and evaluation of preventative measures, and standardized diagnostic approaches leading to the adequate medical management of the epilepsies and lastly a net savings of money, as duplication of effort is reduced.

Thank you for this opportunity to present my views to you.

Mr. KYROS. Thank you, Dr. Wilder.

Dr. SAHS, let me ask you this. What do you think is the most compelling item in the management of epileptic patients?

Dr. SAHS. So far as the management is concerned, I think the first item that one encounters is an accurate diagnosis and this has many, many implications at several levels. Then the next matter is the control

and if the control can be achieved by drugs, this is fine. This is the idea toward which we all try to arrange our treatment programs.

Some patients, however, are not so easily controlled and there is a big gap in our control program so that leaves approximately 40 percent where control is either incomplete or not at all.

The various social, economic, legal and educational matters have been covered this morning.

Mr. KYROS. In control, I remember once talking with some scientists about neurons traveling in nerves and electrical impulses being contained and being discharged in certain ways. This problem sounds like something where the electrical impulses discharged along certain motor pathways are not properly discharged or triggered at the right time.

Is this the kind of problem—this electrical discharge problem—

Dr. SAHS. I like to look on it like what we call a condenser effect. Instead of being discharged arhythmically, many of them discharge simultaneously or quickly, so what we have is literally an explosion in the brain which may involve a localized area or may spread to other portions of the brain.

Mr. KYROS. What do the drugs attempt to do? The ions travel through the nerve cells and change the pattern of electrical discharge so there is a smoother flow, or what happens?

Dr. SAHS. It changes the chemistry of the cell in such a way that the cells do not discharge arhythmically or asynchronously as they do in the epileptic, thus we have a more synchronous action and a freer flow of these impulses.

Mr. KYROS. Why does it take 14 years? I remember when I was in law practice sometimes we came across, many years ago, cases involving epileptic seizures. I remember the drug Dilantin, an anticonvulsant drug. Why does it take 14 years now before we had had a new drug?

Dr. SAHS. This is one of the things I had hoped to talk about, but I tried to keep my conversation brief. The matter of development of new anticonvulsant drugs has almost been at a standstill recently. There perhaps are several explanations for this. The increased possibility of producing a toxic drug, lack of areas in which to maintain controls. There is a cliché going around, "If you want to test a new drug, you had better take your material out of this country." I think that is a deplorable situation, if this is true.

Therefore, the development of new drugs, as I indicated a little while ago, is almost at a standstill.

Finally, we have Tegretol, which may be useful in some patients, but this has been a long time in coming.

Mr. KYROS. We had the FDA in last week. We were doing vitamin and mineral food supplements, and we worked the FDA up and down and they worked us over, so we don't want to talk about them today, but you are not suggesting that the new drug policies of FDA are inhibiting the product of anticonvulsant drugs, are you?

Dr. SAHS. The drug companies are approaching the development of new drugs with considerable caution.

Mr. KYROS. Now do we need more training funds, Dr. Daly, in the area of training physicians as diagnosticians and specialists in the field of epilepsy? What do you think about that?

We are also writing at this time a health manpower act. This committee is writing a health manpower act which has in it considerable funds with many things it wants to encourage—doctors serving in underserved areas, doctors going into family practice, and I don't remember seeing anything in the bill that would say we would help doctors if they picked up epilepsy as a specialty, but what about training for epilepsy?

Dr. DALY. I think it has already been alluded to by Dr. Van Pelt that even with people trained in the neurological specialties, there is a singular reluctance to become involved in the care of epileptic persons. I think there are reasons for this.

Many of the social problems transcend the individual physician's ability to cope with them and he is prone to throw up his hands in despair. We have often inadequate teaching at medical school level of medical students and we have inadequate teaching of residents in pediatrics, internal medicine, and family practice and even in neurology.

I have alluded to the need for advanced care centers for diagnosis and treatment. If such were to exist, then I think the level of education, continuing education and on-going graduate medical education could be significantly improved.

The fact remains it is very difficult to get either young basic scientists or young clinical neurologists interested in the problems of epilepsy. There are problems in trying to find neurologists with competence and interest to serve in these regional Veterans' Administration epilepsy centers.

There is also a great need in the allied health sciences, public health nurses, social workers, vocational counselors, as you have heard this morning, and in some of these specialty areas like EEG technology where it is impossible to obtain adequately trained people.

I believe we are in the sort of vicious circle in which the lack of adequately trained people perpetuates the inadequacy that exists, so I would say, yes, there is a very major and compelling need for training programs in this area.

Mr. KYROS. Epilepsy certainly is not a specialty like orthopedic surgery or cardiology. How do you identify the expert in epilepsy? Is there any mode of identification now?

Dr. DALY. I think, first, there has been less tendency in this country for neurologists to concentrate exclusively on epilepsy than there has been in other countries of Europe where epileptology is recognized at least de facto as an area of subspecialization. I don't know that we need to formally identify somebody as an epileptologist, but I do believe the need exists for centers which will permit advanced training comparable to those, for example, in neuroradiology. This is not a recognized subspecialty, yet we recognize that people need special training in this area and that it may require 1 or 2 years more.

Electroencephalography does have a board of qualifications. The number of people certified is small and there are difficulties in obtaining funds to train electroencephalographers. Because EEG qualification is not part of residency training programs, the usual sources of stipend support for residency training do not exist for the training of encephalographers. Basically the same problems apply to training in epileptology.

I believe that, given somebody who has completed neurology residency training, an additional year or 2 years of training would identify the person as having special competence in the area of epilepsy and one who could attack the existing needs.

Mr. KYROS. What about the drug Mogodon that was mentioned earlier? Why is it not available in the United States, and why is it available in Canada? Do you know anything about this?

Dr. DALY. This drug is one of a group of compounds called Benzodiazepines. It is my understanding that the company producing the drug decided that they did not want to go through the expense of reestablishing the safety of this drug in this country by reduplicating the studies that had previously been made abroad.

If I may, I would like to speak to this point about why the delay of 14 years in introducing a new drug. I served as the chairman of an international commission on antiepileptic drugs. We surveyed drug companies over the entire world. We found there were several problems.

Oddly enough, a number of large drug companies believed no need exists for new antiepileptic drugs. They have fallen prey to the statement that 80 percent of the patients are indeed controlled when we know they are not.

Second, they are reluctant to understate the expense of bringing a drug through clinical testing because as recently as 2 to 3 years ago it cost approximately \$5 million and they felt there was not a sufficient market.

Third, and this problem has now been resolved, the Food and Drug Administration was reluctant to accept drug testing done in foreign countries because it might not meet their rigorous standards. We were able, at the World Epilepsy Congress in Barcelona last September, to get agreement among the Western European nations and the medical groups working on epilepsy in these countries, to adopt the FDA standards for testing, and FDA in turn has agreed to accept studies carried out under these protocols. So, we would hope that we can shorten the testing periods to about a year and one-half and speed the introduction of drugs.

But we do lack in this country adequate populations or groups of patients who have been carefully studied, their types of seizures and type of epilepsy classified, and whose seizures are uncontrollable with the available drugs, who could then be used to study new drugs.

The introduction of such special centers as the VA proposes and those which would presumably develop under a comprehensive care program should do a great deal to encourage the trial of new drugs.

Mr. KYROS. Why don't we have this now? We have all kinds of data on something like smoking, for example, the incidence of carcinogenics and the causality of cancer in patients smoking. Why don't we have the effect of various kinds of drugs on convulsive seizures and their severity? Why don't we have that?

Dr. DALY. I think part of it is a rather complex problem, namely, that in many instances it takes years to discover the effects of the chronic administration of drugs. And I would point to the as yet incompletely understood phenomenon of the effect of antiepileptic drugs

on folic acid metabolism. We don't know what the long-term effects are.

There have been until very recently no studies on the effect of the administration to pregnant women of antiepileptic drugs. Those studies that have now been made suggest that we should look at this problem much more closely.

Mr. KYROS. What does an epileptic woman do if she becomes pregnant? What does she do? Does she take the drug? Does it have side effects on the infant?

Dr. DALY. There are two problems. There is the tendency for pregnancy to aggravate seizures in the mother. There is also evidence that some, probably not all, antiepileptic drugs, particularly when given in the first 3 to 4 months of gestation, may increase the incidence of fetal malformations. Now the incidence is small—90 per 1,000 births—but it is statistically significant and of the order of at least 100 percent increase in the number of fetal malformations. We have absolutely no clue as to what causes this. Some people think it is related to certain of the metabolites of drug transformation in the body, a group of compounds called epoxides. We know very little about genetic differences in metabolism of the drugs. Some women may be peculiarly vulnerable to producing different metabolic products. This area is completely unstudied.

Mr. KYROS. Let me ask you this question, Dr. Wilder. What problems are there in getting new techniques for treating epileptics adopted and utilized?

Dr. WILDER. Primarily, Mr. Chairman, dissemination of information, really. We have developed very active laboratory analysis of drugs and we received samples from many areas of the country. Yet you can move down our own State a few miles and people are unaware of availability.

Now, we have tried through the Epilepsy Foundation of Florida, through the bulletins of the health-related services of the State of Florida, to disseminate information, and I think we have been successful to a certain extent.

We tried to provide a service for the State of Florida and other areas in the United States. It primarily is, I think, one of education, one that a national spotlight would serve the purpose of making such new advances available to the medical profession at large, and even more so to the patient population.

I found oftentimes that a mother can enhance the treatment of her child when she goes in and asks her doctor, "Why aren't we using blood levels that they are doing at the University of Florida," so the doctor gets on the phone and says, "What is this?"

So I think it is education. It is attention to the things that are being done in a way that will spread the word.

Mr. KYROS. Do you feel you have all the medical information at hand needed to treat the various epilepsies?

Dr. WILDER. No, sir. There is a great deal of information we need. We mentioned some of these earlier. One is we need to know much more about genetic factors. We need to know more about the effect of anticonvulsant drugs. For example, the most widely used anticonvul-

sant drug and the most effective, Dilantin—diphenylhydantoin—only now are we really probing into the metabolism and the other effects that this drug may have.

We need a great deal of clinical and more basic research in this area. When I mentioned the amount \$6.4 million, I think this is woefully inadequate for a problem of the magnitude that the epilepsies present.

Mr. KYROS. Mr. Symington.

Mr. SYMINGTON. Dr. Wilder, this Dilantin that is one of the drugs that is used; aren't there studies that show it may cause birth defects?

Dr. WILDER. Dilantin has been implicated in this way, sir. The studies that have been done are what I would consider rather poorly controlled and there are huge populations of pregnant women who have been on anticonvulsant drugs, Dilantin being the most commonly used.

Whether the Dilantin per se has a teratogenic effect, or whether it is interaction with perhaps folate, of which Dilantin tends to inhibit the absorption and prevent the conversion of some of the folate forms, this needs to be clarified.

In my own practice I had much rather the patient continue on her anticonvulsive drugs than risk provoking a status epilepticus or serious seizure situation. The risk is much higher for that than the smaller risk for a possible birth defect.

Mr. SYMINGTON. Do these studies indicate at what point in the pregnancy the effect is likely to occur?

Dr. WILDER. It would occur in the formative period of the fetus, in the first trimester of pregnancy, and oftentimes by the time a pregnant woman realizes she is pregnant the drug, if it has an effect, may have already had the deleterious effects.

Mr. SYMINGTON. We use this word "studies" loosely. How conclusive are those and where are they? Have you got them?

Dr. WILDER. I beg your pardon?

Mr. SYMINGTON. Where are these studies that indicate that this drug may be harmful?

Dr. WILDER. There are collections of pregnant women and their babies who have been on anticonvulsive drugs for a period of time during their pregnancy, and it is merely a matching-up of the malformations in their offspring as opposed to a control group.

Mr. SYMINGTON. What is the increase?

Dr. WILDER. It is about twofold.

Dr. DALY. There was a study published from Great Britain this past year in which they used three populations of patients. They used a population of epileptic women who were pregnant and receiving anti-epileptic drugs and who had an incidence of 90 per 1,000 births. They used a second population of epileptic women who were pregnant but not receiving antiepileptic drugs with an incidence of 60 per 1,000 births. And they used a third population of nonepileptic women not receiving drugs with an incidence of 30 per 1,000. There was an increase of the order of magnitude of 100 percent which appeared to be introduced by simply having epilepsy. When the epileptic women were also on either phenobarbital or diphenylhydantoin, there was an additional 100-percent increase, so it seems inferentially clear that there is an effect of the antiepileptic drugs.

There is a collateral line of evidence which was obtained from the collaborative perinatal study carried out in this country under the U.S.

Public Health Service and NINDS, and again there is a slightly increased incidence of fetal malformation rate in pregnant women on antiepileptic drugs.

I would emphasize this problem is important and it needs much more careful study than it has had.

Mr. SYMINGTON. So it is twice as many women with epilepsy have malformed embryos than those who are not epileptics, and then twice as many victims of epilepsy who take a Dilantin-type drug have such problems as those who don't.

I take it those which don't take that drug and which are epileptic take something else to control their seizures.

Dr. DALY. These were patients with infrequent seizures who for this reason were not on any drugs.

Mr. SYMINGTON. And Dr. Wilder says he would still rather take a chance, even knowing that this factor of 2 to 1 exists, because of the danger in allowing the women to go untreated.

Dr. DALY. Don't misunderstand me. The risks of miscarriage or abortion from a status epilepticus, recurrent seizures, I think would be much greater, and also we are still talking about a small number of patients. I am suggesting that there is reason to think these are not innocuous compounds, but we need to have more than inference or supposition. We need concrete data, and this is not available.

Mr. SYMINGTON. Did the control groups used carry out your prediction that they would indeed lose their children without treatment? Is that demonstrated in the control groups?

Dr. DALY. You mean the epileptic group without medicine?

Mr. SYMINGTON. Yes, sir.

Dr. DALY. They had a greater risk than nonepileptic women, but the risk was not as great as epileptic women on antiepileptic drugs.

So there is a sort of increasing hierarchy of risk between not being epileptic at all in which you still have some risk; being epileptic and in which the risk becomes greater; and being epileptic on antiepileptic drugs in which the risk is still greater.

Dr. VAN PELT. Could I enlarge on what Dr. Daly is saying? I think there may be a little confusion here. The problem is talking about severity of the seizure disorder.

There are people that have very occasional seizures even if they are not receiving medication, and these—I am not that familiar with the study that Dr. Daly referred to—but there are certainly women who go through pregnancy without taking anticonvulsants because they may not be fully aware of the fact they are epileptic.

But people who have bad seizures and do not receive medication are at extreme risk of having unfavorable outcome from their pregnancy.

Mr. SYMINGTON. So we have to do research on these drugs?

Dr. DALY. Yes, sir.

Mr. SYMINGTON. What is being done about that at the moment? Is there a shortage of money, of direction? Is this something that you think Mr. Kyros' bill would have some relevance to?

Dr. WILDER. Yes, sir, I would say there is a definite shortage of research funds in this area. There is a great need to expand clinical-oriented drug research in direct relation to epilepsy as well as other conditions, but certainly in epilepsy. Yes, sir.

Mr. SYMINGTON. Are there other risks of drugs of this kind other than the ones we have been discussing concerning fetal malformation that are as yet untested and give us cause for concern but we do not yet fully understand them?

Dr. WILDER. It is always dangerous to take any drug, Mr. Symington. As I am sure you are aware, the anticonvulsant drugs have been implicated in producing various blood disorders, kidney problems, liver problems, tumor activation. The risk is again extremely low, but there is always risk in taking drugs.

I think the antiepileptic compounds as a whole are probably less dangerous than many groups of drugs that people take. One of the things that attests to this fact is that I have many patients that have been taking Dilantin for 20 or 25 years; provided they brush their teeth faithfully, they have few gum problems and few other problems.

But one of the things that is remarkable about the anticonvulsant drugs is when one embarks on treating a patient with them he is looking forward to probably treating a patient for 10, 15, 20 years or perhaps the remainder of his life.

Mr. SYMINGTON. Thank you very much, Mr. Chairman.

Mr. KYROS. Thank you very much, gentlemen. We certainly appreciate having your testimony and I am sure it will be helpful to the full committee. Thank you very much.

Our next panel is made up of four distinguished men who represent a wide range of viewpoints in the social and rehabilitation field of epilepsy. The chairman of the panel is Mr. Harold Russell, widely known throughout the country for his work as chairman of the President's Committee on Employment of the Handicapped.

I would ask Mr. Russell to introduce his copanelists.

#### STATEMENTS OF SOCIAL AND REHABILITATION PANEL:

**HAROLD RUSSELL, CHAIRMAN, PRESIDENT'S COMMITTEE ON  
EMPLOYMENT OF THE HANDICAPPED;**

**DANIEL SINICK, Ph. D., PROFESSOR OF EDUCATION, DIRECTOR,  
REHABILITATION COUNSELOR EDUCATION PROGRAM, AND  
EDITOR, VOCATIONAL GUIDANCE QUARTERLY, GEORGE  
WASHINGTON UNIVERSITY;**

**ANTHONY J. ARANGIO, Ph. D., ASSOCIATE PROFESSOR, SCHOOL  
OF SOCIAL WORK, UNIVERSITY OF TEXAS AT ARLINGTON,  
AND HEAD, COMMUNITY PLANNING AND ADMINISTRATION,  
UNIVERSITY OF TEXAS AT ARLINGTON; AND**

**JACK McALLISTER, DIRECTOR, DIVISION OF RETARDATION,  
DEPARTMENT OF HEALTH AND REHABILITATIVE SERVICES,  
STATE OF FLORIDA**

Mr. RUSSELL. Thank you, Mr. Chairman.

I speak for all of the panel when I tell you we appreciate the opportunity to testify on this bill which affects so many people.

As chairman of the President's Committee on Employment of the Handicapped, I would like to say a few words about employment for Americans who happen to have epilepsy. May we consider these facts:

Fifty percent of all persons with epilepsy can have their seizures

brought under complete control by medication. Another 30 percent can have their seizures lessened in this way.

It is estimated that one person in every 50 has epilepsy. That means that approximately 4 million Americans have epilepsy, of whom approximately 1 million are adults.

The rate of unemployment of persons with epilepsy is between 15 and 25 percent—much higher than the national unemployment rate of around 5 percent. In other words, the unemployment rate of men and women with epilepsy is three to four times higher than for all other Americans.

If persons with epilepsy had the same unemployment rate as others, there would be 50,000 unemployed. But they don't. Their rate is 15 to 25 percent—and, again, let's go down the middle and use 20 percent. In numbers, this is 200,000 unemployed.

The difference between what might be called a normal unemployment rate and the unemployment rate of persons with epilepsy is 150,000. These 150,000 men and women, we might conclude, are jobless for reasons having to do with their epilepsy. Perhaps employers won't have them. Perhaps society rejects them. Who really knows?

According to Dr. Ronald Conley, economist at the Department of Health, Education, and Welfare, the lifetime earnings of the average person are around \$750,000. If that sounds high, it's because Dr. Conley took into account a continuing inflation into the future.

Now if we apply Dr. Conley's figure to the 150,000 men and women who are unemployed for reasons having to do with their epilepsy, we see that they are being deprived of lifetime earnings totaling the mind-boggling amount of \$112 billion. That's not million, but billion.

That is an amount equal to one-third of the entire Federal budget for this fiscal year.

What an appalling loss—all because too many people with epilepsy are being deprived of their rightful opportunity to work, not by the actual fact of their disability—for remember, 50 percent of all seizures can be completely controlled—but by the myth of their disability that still lurks in the minds of so many human beings.

So much for the way things have been. What about the way things are likely to be? I do see hopeful signs on the horizon—but to reach them will require a wholehearted commitment by this country and by all of us concerned with the destinies of those with epilepsy.

One of the hopeful signs is the Vocational Rehabilitation Act of 1973, which stresses that priorities in rehabilitation services are to go to those who are severely handicapped. To make certain there is no question about it, the law itself defines a severe handicap as one requiring multiple services over an extended period of time, resulting from a list of conditions, one of which happens to be epilepsy.

Another hopeful sign is section 503 of that same act, which requires businesses holding Government contracts to have affirmative action programs on hiring handicapped persons. Not only must a company open its doors to all handicapped applicants who come in, it must make some outreach efforts to seek out qualified people.

Half of all the businesses in America have Government contracts. And so, half of all the businesses in America are going to have to step up their efforts to hire those who are handicapped.

Still another hopeful sign is a refreshing new spirit by handicapped persons themselves, of demanding their full rights of first-class citizenship in America, and all that first class citizenship implies. This, of course, also includes an end to job discrimination.

President Ford made note of this new spirit in his keynote address at the recent Annual Meeting of the President's Committee on Employment of the Handicapped. He said:

We are leaving an older day in which good-hearted people gave careful thought to what they think is best for handicapped people. And we are coming into a newer day in which handicapped people are expressing themselves, are making their voices heard, are arriving at their own decisions.

An article in a recent issue of U.S. News and World Report noted the same spirit. It said:

Today, unwilling to languish on the fringes of U.S. society, the handicapped are lobbying, filing legal actions, and demonstrating in the new spirit of what some call crutch power.

So there is a problem and there is a promise.

Now what can we do to help translate the problem into the promise?

We can encourage men and women with epilepsy to prepare for the labor market. Gone are the days when a person can merely say, "Here I am, ready for work; I'll do anything." We are in an age of specialization, an age of skills. Vocational rehabilitation can provide that specialization, those skills—with priorities going to those with epilepsy.

We can encourage employers to give more opportunities to qualified people with epilepsy. And we can do this by spreading the facts: 50 percent of all seizures completely controlled, 30 percent minimized, with proper medicines. These are reassuring facts, and employers need to be reassured, as a means of melting away the stereotypes of epilepsy that still lurk in their minds.

And we can take our own inventories of qualified people with epilepsy ready and willing to work, so that when employers seek them out, under section 503 of the Rehabilitation Act, they will be available.

There is a new light on the horizon. Together, we can march toward it. The Kyros Bill 13405 is a big step in the proper direction.

Thank you.

Mr. KYROS. Thank you, Mr. Russell, for a fine statement. I understand you have to catch a plane by 3:30 so if we could ask you a couple of questions before you go.

You talk about section 503 which requires businesses having Government contracts to take affirmative steps on hiring handicapped persons. And also about the President's message on the handicapped which is a reaffirmation of a fine American policy.

Are there any other specific things you think we should be doing besides this bill which will focus some spotlight? Anything in terms of employment, rehabilitation or vocational rehabilitation for epileptics as a class?

Mr. RUSSELL. Yes, sir, Mr. Chairman, I think one of the big problems we face in the employment of people with epilepsy is the fact that there is a sad lack of understanding of their capabilities.

Primarily there must be a program of education to employers to show them that the person placed in the right job can do his job as well as if he had no disability including epilepsy.

So, if we can bring forth this affirmative thinking along with the compliance program of section 503 of the Rehabilitation Act we can do a great deal for handicapped people and also a great deal for American business providing the kind of people who can do the job that business requires today.

**Mr. KYROS.** Thank you very much.

Appearing with you on your panel is Dr. Daniel Sinick, professor of education at George Washington University. Also Dr. Anthony J. Arangio, associate professor of community planning and administration, School of Social Work at the University of Texas at Arlington. And Mr. Jack McAllister, director of the division of retardation of the Department of Health and Rehabilitative Services, Tallahassee, Fla.

Gentlemen, I want to welcome you all to the committee, I understand our next witness will be Dr. Daniel Sinick.

#### STATEMENT OF DANIEL SINICK

**Mr. SINICK.** Thank you. I am Daniel Sinick, professor of education and director of rehabilitation counselor education at George Washington University in Washington, D.C. Currently editor of the Vocational Guidance Quarterly, which is the professional journal of the National Vocational Guidance Association. I am past president of the American Rehabilitation Counseling Association and the Council of Rehabilitation Counselor Educators. I am also author of a chapter in the forthcoming book, "Epilepsy Rehabilitation."

It is indeed a privilege to have been invited to share with you some views on epilepsy and the rehabilitation process, and on the professional needs of those preparing to work with persons with epilepsy, with the families of such persons, and with employers.

Harold Russell, the distinguished Chairman of the President's Committee on Employment of the Handicapped, indicated some of the problems in attempting to gain employment.

His testimony indicates that there is still a long way to go in educating employers and correcting the myths and stereotypes developed over the ages.

While employers constitute a key element in the vocational rehabilitation process, rehabilitation counselors and other helping professions, as well as paraprofessionals, that make up the rehabilitation team need the best available information so that they can modify their own as well as employer's myths and stereotypes. Some up-to-date information is available, but its utilization in preservice and in-service training is minimal because of the apparently low priority given epilepsy by Federal and State agencies.

Despite a paucity of hard data dealing specifically with epilepsy, evidence indicates that its priority is much lower than that accorded such disability categories as mental retardation, mental illness, and most recently drug abuse—since the national attention it received

in 1968. Federal figures show a decline, indeed, in the proportion of persons with epilepsy rehabilitated by the Federal-State program. In fiscal 1966, of all clients successfully rehabilitated by the Government-sponsored program, only 2.1 percent were persons with epilepsy. In fiscal 1970, this tiny figure became ever smaller, declining to 1.7 percent. In fiscal year 1972, the figure declined still further to 1.5 percent. The question of, Why this trend? is certainly cause for concern. Especially so when the total number of rehabilitations nationally is at an all time high.

Federal figures also indicate that close to a third of the applicants for rehabilitation services who have epilepsy are not successfully rehabilitated, despite the advances in the medical management of epilepsy. Why were these persons with epilepsy unable to benefit maximally from the vocational rehabilitation process? What benefit did they gain, if any? Was the major problem a matter of misplaced priorities, insufficient numbers of deployed personnel inadequately prepared to rehabilitate persons with epilepsy?

While these questions call for relevant research to produce hard data on which answers might be based, it seems reasonably realistic to expect an increase in successful rehabilitations of persons with epilepsy if certain steps are taken. One step is to assure a higher priority to this disability category than the low priority it appears to have been accorded in the past. Another step is to foster further advances in the substantive aspects of the medical management and vocational rehabilitation of persons with epilepsy. An additional step is to facilitate the dissemination and implementation of the latest pertinent knowledge, which is needed by rehabilitation counselors and other helping personnel, by clients themselves and their families, and by employers.

That such information can be put to effective use in attitude change and ultimate rehabilitation has been demonstrated in the area of mental retardation, where comparable Federal figures are far more favorable. Instead of the exceedingly low percentages associated with vocational rehabilitation of persons with epilepsy, about 12.5 percent of persons with mental retardation have been successfully rehabilitated during the last 10-year period. This more desirable rehabilitation rate has been brought about as a direct result of a sound national plan by a Presidential panel on mental retardation in 1962. The time is obviously past due for a unified national thrust for those with epilepsy.

Mr. KYROS. Thank you, Dr. Sinick.

I understand you also have to leave.

Mr. SINICK. I teach and I have a class coming up at 4 o'clock.

Mr. KYROS. I have just a couple of questions for you.

What you point out in your statement is, in essence, that there is not much sense in rehabilitating people, in going to that great effort, if employers have not been educated and won't even hire them. So you have a twofold problem.

Mr. SINICK. Yes, sir.

Mr. KYROS. How do you get to the employers? What do you do to employers to educate them? They are trying to make a living in a difficult period and they have their problems. Why should they take

someone who has epilepsy which gives them cause for concern? It might mean putting a guard on a skill saw or on a lathe which they don't want to do.

Mr. SINICK. Rehabilitation counselors who try to obtain employment for persons with epilepsy have a way of preparing for one of the things that employers will say. They have a list of objections that employers ordinarily make and things to say to counter these objections but it is fairly mechanical.

It is hard for employers to accept statistics which are based upon studies that show persons with epilepsy have no more accidents than others without epilepsy or that their absenteeism rate is no less favorable or things of that kind.

They are concerned with a position they have to fill with a person with epilepsy and they have a lot of vague fears and anxieties based upon lack of knowledge and it is hard—actually the professionals in the field are inadequately prepared to counter these objections of employers.

So, education has to occur not only on the side of employers but there has to be an enhanced expertise on the part of the helping professionals.

Mr. KYROS. How about the preparation of rehabilitation counselors. Is that adequate to serve persons with epilepsy? Are we training that kind of counselors today?

Mr. SINICK. The realities of funded programs suggest that the same priorities are accorded the preparation of rehabilitation counselors that are nationally sponsored and so without priorities and consequent funding to support the preparation of rehabilitation counselors with particular expertise to deal with persons with epilepsy, the programs do not have the wherewithal or the inclination to put their priorities where that particular need it.

Mr. KYROS. Thank you very much, Dr. Sinick. I appreciate your taking time out to come here today.

Our next witness will be Dr. Anthony J. Arangio from the University of Texas.

Dr. Arangio, welcome to the committee.

#### STATEMENT OF ANTHONY J. ARANGIO

Mr. ARANGIO. Gentlemen, I appreciate the opportunity to appear before the committee to testify regarding the need for the establishment of a National Advisory Commission to develop a national plan for the control of epilepsy and its consequences.

I am Anthony J. Arangio, Ph. D., associate professor and head of the community planning and administration, School of Social Work at the University of Texas, and vitally concerned and involved with the needs of persons with epilepsy.

If I may be allowed one personal reference in deference to the chairman. In the research that I have conducted and scholars have noted that epilepsy was a word that was designed by the Greeks and I think it should not go unnoticed that one with Greek ancestry may once again help to redefine that word in our country.

Mr. KYROS. Someone told me that since the Greek language was

used to identify all these diseases the Greeks must have had a lot of them in those days.

Mr. ARANGIO. Hopefully an Italian like myself may be able to help you out, Mr. Chairman.

You have heard the consumer panel discuss in great detail the stigmata attached to epilepsy. My testimony in further detail goes through the same kind of encounters that either parents or people themselves with epilepsy go through. And I think it really was very eloquently stated by the panel.

I don't wish to go through the entire thing.

I also wish to share your dismay with Dr. Bernstein's view. I think this dismay may be an understatement.

As we know, epilepsy is not contagious, but fear is. Many of the present day stigmas attached to epilepsy, both psychological and social, originate in an unfortunate history linking epilepsy with possession by demons, magic, and mystical philosophies.

These accounts, seen as history and literature, are interesting in that they describe early attitudes toward epilepsy, but they have now become bases for generalizations about epilepsy. Many of these early myths have been destroyed by recent research but many others continue to exist, which have led to prejudice and discrimination against those who have epilepsy. For example, some recent research figures show that there is greater prejudice against persons with epilepsy than against persons with a mental illness, yet studies also show that measured attitudes are better today than say 20 years ago.

Studies by Goldin have indicated that the psychosocial functioning of the person with epilepsy is most accurately described as a constant interaction of social systems in which he is deeply involved and which greatly influence his activities and adjustment to life. These systems include the family, the school, and vocational and health and welfare agencies, systems all crucially important to healthy psychosocial adjustment.

The general public's attitudes toward epilepsy create a stigma that compounds already existing attitudes toward the handicapped. This stigma can have only negative effects on the child with epilepsy. Parental attitudes and the home environment are important for all children, but even more so for the child with epilepsy. Fears, anxieties, and lack of specific information may create tensions in the home, which then strongly influence the child's adjustment to activities outside the home. In what ways does the onset of epilepsy upset, alter, and strain the family's daily living patterns?

Family members may react in a number of ways to the child with epilepsy. Parents may become depressed over the loss of a perfectly normal child, they may feel unable to cope with many of the problems caused by their child's epilepsy, and they may also become hostile, angry, defensive, and resent the child. The additional losses of time, money, and social contacts may place a heavy burden on the family's patience and resources. Since the child may receive special attention and privileges from his parents, his brothers and sisters may resent the added attention he receives.

What effect does all this stress have on the child who has epilepsy? He is faced with the many problems of understanding what he has,

the necessity of taking medication, and the reactions of his family, teachers, and friends. He is the one most closely affected by his epilepsy which may create complex self-identity problems. The child who faces many of these social and family problems may compensate by fighting back. Thus, while some persons with epilepsy may display behavioral problems, it should be remembered that these may be normal reactions to abnormal situations.

When the child reaches school age, teachers' attitudes can further set the stage for acceptance of the child by his peers or they can help to further cement the stigma of epilepsy in other children's minds. Before a seizure occurs, teachers may treat the child with epilepsy like any other child. However, the moment the child has a seizure, he is set apart from others and becomes an epileptic—no longer a child who happens to have epilepsy. Teachers become wary, other children are influenced by the teacher's behavior, and the child is frequently ostracized. Other parents may refuse to let their child play with him and the normal activities of growing up are suddenly closed to the child—closed overwhelmingly by the public's attitudes toward epilepsy, not the epilepsy itself.

As others will probably testify, problems of employment for the handicapped person still exist. Concerned about the need for extra supervision, possible absenteeism, and the ability for sustained work, potential employers are reluctant to hire persons with epilepsy, and individuals dealing with employers have been only partially successful in altering such fears. Most employers, before they will consider hiring a person with epilepsy, must have had previous positive experience with hiring them or know of another employer who had had such experience.

If employers would be more realistic in their hiring practices, many people with epilepsy could be employed, for many recent studies have shown that often people with epilepsy have less absenteeism than other workers, need no more supervision, and in fact are more conscientious about their work than others. However, the stigma of epilepsy, more than any other reason, keeps them from finding and keeping a job.

Another area also exists where the stigmas attached to epilepsy have had great impact—State legislation affecting persons with epilepsy:

Drivers' licenses.—The most common requirement for persons with epilepsy is medical certification of seizure control over a specified period, and license applications in a number of States specifically ask about one's history of epilepsy. Many of these restrictions are legitimate, for if a person's epilepsy is not well-controlled he should not be driving. On the other hand, recent studies have indicated that most accidents involving persons with epilepsy were not caused by the seizure itself. In spite of this fact, as of 1972, one State still prohibits the licensing of persons with epilepsy, totally, yes, sir.

Well, there is an exclusion clause and after a great deal of study it still is on the books as excluding the person with epilepsy, yes, sir.

And I have that State and I won't say unless you ask me—

Mr. KYROS. What State is it?

Mr. ARANGIO. Mississippi.

Mr. KYROS. My goodness.

**Mr. ARANGIO.** In the area of marriage—although no legislation in the United States is directed toward preventing the marriage of persons with epilepsy, the fact that as late as 1965 three States still prohibited this is another appalling indication of the scope of the stigma attached to epilepsy.

**Sterilization.**—As of 1972 nine States reported sterilization laws applicable to persons with epilepsy. The laws in each of these States, except for one, authorize the sterilization of inmates with epilepsy under certain prescribed conditions, even though there is presently no absolute evidence linking hereditary factors to the occurrence of seizures following head injury or trauma to the brain. Since these are believed to be two major causes of seizures, many authorities have concluded that heredity plays a minor role in the majority of seizures.

**Special education.**—As of 1972 only three States have legislation provisions for special education of children with epilepsy, who, by reason of their epilepsy, cannot profitably or safely attend public school.

**Insurance.**—In light of more modern methods and new advancements in the treatment and control of epilepsy, the fact that persons with epilepsy will report difficulty in obtaining life, health, and auto insurance at reasonable rates, if at all, is just one additional indication of the stigma attached to epilepsy. In many States insurance is virtually impossible to obtain if one has epilepsy.

There is one additional area which I would like to briefly explore in relation to the stigma of epilepsy and that is the realm of public attitudes. As far as social prejudice and stigma are concerned, there has been a change over the years in the public's attitudes toward persons with epilepsy.

The American Institute of Public Opinion has traced American attitudes toward persons with epilepsy from 1949 through 1974. Over the years, the number of people favoring employment for a person with epilepsy has increased although in 1974 an estimated 11 million people were still opposed to persons with epilepsy working, and an estimated 7 million people were still opposed to their child playing with a child who has epilepsy. In general these statistics indicate that there is still an appalling number of people who are uninformed about most medical and social aspects of epilepsy.

In summary, the basis of most prejudice is fear, and in the case of public prejudice against persons with epilepsy, the fear is of the sudden loss of physical and emotional control. The person with epilepsy is frequently feared and often hated because without warning and in any situation he may unpredictably lose control of his consciousness and movements. The suddenness of the attack, as well as the lack of warning, contributes greatly to this prejudice.

These facts and observations that I presented to you are fine and I hope informative, but where do we go from here? How much longer will the person with epilepsy absorb the stigma of his symptoms?

While the attitude measures improve, at least on paper, what is really happening to the individual in the areas of education, jobs, drivers licensing laws, et cetera? Obviously, State legislation affecting persons with epilepsy is not consistent among the States. One of the beneficial by-products of the National Commission is the formulation

of model legislation statutes in every State, which are consistent with each other.

Without a doubt, a National Advisory Commission is needed now to review the numerous facets affecting this disability group and to identify the positive approaches as well as the gaps as it concerns the epilepsies. For only through a coordinated effort will the roots of prejudice toward epilepsy ever diminish.

Mr. KYROS. We will have to suspend for a few minutes. I have to answer that vote, which is an amendment, and we will recess the committee for 10 minutes. We will be right back.

[Brief recess.]

Mr. KYROS. The committee will come to order.

The last witness on the social and rehabilitation aspects of this problem is Mr. Jack McAllister, director, Division of Retardation, Department of Health and Rehabilitative Services, Tallahassee, Fla.

Mr. McAllister, welcome to the committee.

### STATEMENT OF JACK McALLISTER

Mr. McALLISTER. Thank you, Mr. Chairman, with your permission I have submitted a written statement which I would like included in the record, and in the interest of time I believe I would like to summarize that statement.

Mr. KYROS. Without objection, so ordered [see p. 108].

Mr. McALLISTER. I am most pleased and gratified to be able to be here to express enthusiastic support for the bill which you have introduced calling for a National Commission on Epilepsy.

I speak to you today both as a State administrator and as chairman of the Development Disabilities Planning and Advisory Council in Florida.

We have made significant beginnings toward progress for persons with epilepsy in Florida as an outgrowth of the developmental disabilities movement. I am sure you are aware that the honorable chairman of this subcommittee, Mr. Paul Rogers, was the sponsor of that legislation in 1970.

What has occurred in Florida is that the State of Florida has teamed up with the private sector and in appropriating a planning grant from developmental disabilities to the State epilepsy foundation, a conference was held of statewide significance bringing in top officials as well as voluntary leaders throughout the State which resulted in the secretary of the department of health and rehabilitative services calling for a 5-year action plan for epilepsy in the State of Florida.

A task force was appointed which came up with that 5-year action plan, Mr. Chairman, and I have a copy of it here with me today.<sup>1</sup> That report contained 88 very specific recommendations, as well as target dates for their completion, and pinpointed those people in both the

<sup>1</sup> "Florida's Five Year Action Plan for Epilepsy," a comprehensive services plan designed to focus upon the needs of persons suffering from epilepsy, a cooperative effort of Florida's Developmental Disabilities Planning and Advisory Council; Florida Epilepsy Foundation; Department of Health and Rehabilitative Services, Division of Retardation and Division of Planning and Evaluation. This publication may be found in the committee's files.

executive branch of Government and the private sector having responsibility for carrying out the various action points.

To date, of the 88 action points which were brought forth in that task force's 5-year action plan, after 9 months of implementation 36 have been completed or are on their way toward completion.

I would like briefly just to summarize a few of the areas which resulted from that particular plan. Recommendations which have been implemented include, in medicine, a system of blood level analyses through which we are reaching more of the general people throughout Florida who are medically indigent. This diagnostic procedure is being used all throughout the State through the cooperation of Dr. Wilder whom you heard from earlier.

In addition, the State's division of health has expanded its program of providing for anticonvulsant drugs to the medical needy.

In education, legislation has been enacted to provide for school health services with primary emphasis on having available, a nursing aide in every school, trained to provide improved first aid for the child with grand mal seizures.

Also, epilepsy has been defined by the board of education as a category of physical handicap in State special educational guidelines.

In the area of transportation, documentation was completed on sound administrative procedures to be used in licensing drivers with epilepsy and other disabilities. These results confirm the need for legislative action to avoid possible discrimination.

Now, to further the implementation of the plan, our State legislature has recently appropriated \$562,500 to provide a statewide system of information and referral, social casework services, and for the provision of neurological assessment for the needy.

Additionally, in the area of employment, legislation was enacted in May to provide subsidization by the State of around \$500,000 to sheltered workshops who served the substantially handicapped developmentally disabled, including the person with epilepsy.

In addition, our State division of vocational rehabilitation has assigned one counselor to serve in each of the State's 16 regions, specifically for persons with epilepsy. These are just a few of the examples, Mr. Chairman, of what Florida has been able to produce through the use of a 5-year action plan.

We feel that the action plan is highly needed and significant, because it serves as a base line document for instigating administrative change, as well as for formulating this very needed legislation.

There is an old saying that planning without action is futile, but action without planning is fatal.

We commend you for your bill, Mr. Kyros, calling for the National Commission on Epilepsy, for a long-range plan for persons with epilepsy.

We feel that it is vitally significant and highly needed, and we hope that you will press forward to its passage.

[Mr. McAllister's statement follows:]

STATEMENT OF JACK McALLISTER, DIRECTOR, DIVISION OF RETARDATION, DEPARTMENT OF HEALTH AND REHABILITATIVE SERVICES, STATE OF FLORIDA

Mr. Chairman and members of the Subcommittee, it is with a great deal of pleasure that I have the opportunity to emphasize the intense need to support

the Bill before you which calls for a *National Commission on Epilepsy*. I am Jack McAllister, Director of the Division of Retardation in the Department of Health and Rehabilitative Services for the State of Florida.

I would like at this time to describe some of the events taking place in behalf of persons with epilepsy in Florida. As the Honorable Chairman of this Subcommittee (Paul Rogers) was the sponsor of the Developmental Disabilities legislation in 1970, you will be pleased to know of the inroads established as a direct result of this mandate.

For example, the combined efforts of the Florida Epilepsy Foundation, Florida's Department of Health and Rehabilitative Services Division of Retardation, Developmental Disabilities Advisory Council and significant action by Governor Ruben Askew, have resulted in two years of exemplary action planning and specific steps to coordinate existing resources, identify areas of unmet needs and crystalize the State's responsibility for services to persons with epilepsy.

In July, 1972, a Developmental Disabilities Planning Grant was awarded to the Florida Epilepsy Foundation which provided the vehicle for an intensive, State-wide planning effort which culminated in a *Five-Year Action Plan*.

A copy of the finished *Five-Year Action Plan for Epilepsy* was presented to each State agency in Florida (which I wish to submit for the record<sup>1</sup>). This Plan was identified as capable of providing services to persons with epilepsy. A majority of the agencies were represented on the Developmental Disabilities Council (DD) and, therefore, had been involved early in the planning.

Progress to date in the implementation of the *Five-Year Plan for Epilepsy* has moved along rather well for this long ignored problem area and thus far, this long-range Plan has proven highly productive in terms of progress for persons with epilepsy. For the Plan serves as a blueprint for bringing about beneficial administrative actions as well as a sound base-line documentation for framing future legislation.

Allow me to list but a few of the recommendations, in the various areas:

In *Medicine*, blood level analyses should reach more of the general public throughout Florida who are medically indigent as a screening and diagnostic procedure.

In *Education*, legislation should be enacted to provide a program of school health services with primary emphasis on having a nursing aide available in every school trained to provide improved first aid for the child with grand mal convulsions.

In the area of *Transportation*, documentation was completed on sound administrative procedures to be used in licensing drivers with epilepsy and other disabilities. These results confirm the need for legislative action to avoid possible discrimination.

In the *Administrative* realm, consideration is being given to change of the name and responsibility of the Division of Retardation to be consistent with Developmental Disabilities, thereby focusing on not just one disability group, but on the population described in the mandate.

While many other pertinent recommendations were made in areas such as legal problems; day care; employment and recreation; I would now like to describe a few visible positive steps which have just recently taken place.

For example, the Florida State Legislature has appropriated \$562,500 to provide a State-wide system of information and referral, social work services, and the provision of neurological assessment for the needy.

In the area of *Employment*, legislation was enacted to provide subsidization by the State of around \$500,000 to sheltered workshops who served the substantially handicapped developmentally disabled, *including the person with epilepsy*. These funds should serve as an incentive to workshops to give greater attention to these persons.

In addition, the State Vocational Rehabilitation Agency has assigned one counselor to serve in each of the State's 16 regions. Those assigned will be receiving intensive training in epilepsy rehabilitation during September of this year and work closely with the Epilepsy Foundations throughout the State.

Also of significance is the fact that blood level analyses of anticonvulsant medication was to be completed on all institutionalized clients of the Department of Health and Rehabilitative Services within this year to upgrade medical care in all State institutions.

<sup>1</sup> May be found in committee's files.

This is but a sampling of the progress derived to date from the *Action Plan*. A Plan which served as a blueprint for bringing about beneficial administrative actions as well as a sound base-line documentation for framing needed legislation. We highly recommend that a similar long-range action plan be developed for the nation—and for this reason, urge your consideration of the Bill before you calling for a National Commission on the Epilepsies.

The Five Year Action Plan for Epilepsy in Florida has proved to be highly successful, and I feel strongly that the establishment of a National Advisory Commission to develop a National Plan for the Control of Epilepsy and its Consequences will prove highly successful for the Nation.

Mr. KYROS. Thank you.

What about the various agencies that you have in Florida? You know, other kinds of administrative agencies, have they made commitments to the plan?

Mr. McALLISTER. Yes, they did. We have an umbrella agency called the department of health and rehabilitative services, where we have 11 divisions. I have the retardation agency, which is also the administering agency for developmentally disabled.

We also have vocational rehabilitation and public health and family services, which is our welfare, and all of the other agencies.

But in addition, the State department of education has made commitments on the basis of this plan, as has the department of transportation, and other departments of government which are not in that umbrella agency.

Mr. KYROS. You feel clearly there should be some kind of a long planning, no matter what happens with our commission, somewhere that long-range planning has to come out.

Mr. McALLISTER. I think you have to have a focal point, Mr. Chairman. The plan gives you not only the focal point, but it makes people think about what they are doing or they are not doing for persons with epilepsy.

Many agencies have money which can be brought to bear on the needs of persons with epilepsy, if the need is highlighted and if they are told what is needed and a timeframe is assigned to that.

Mr. KYROS. Has the Florida plan produced the significant administrative changes you have seen?

Mr. McALLISTER. It certainly has. I have just highlighted for you the appropriation of better than a half million dollars for epilepsy, as well as the workshop subsidy bill of a half million dollars.

We are estimating at this time that benefits which have accrued administratively to persons with epilepsy probably equal two to three times what has been appropriated directly.

Mr. KYROS. So, as you explain, I think that the national plan, if we could formulate a national plan, would try to do what Florida has already led the way to doing.

Mr. McALLISTER. Absolutely, yes, sir.

Mr. KYROS. Well, thank you both very, very much, and we certainly appreciate your taking the time necessary in coming to give your testimony to the committee.

Our final panel today will discuss attitudes, information, and education.

I certainly appreciate these gentlemen and ladies waiting so long.

We have with us Dr. Scott Simonds from the School of Public Health, Ann Arbor, Mich., University of Michigan; Mr. John D.

Furman, Jr., Cox Broadcasting Co., Atlanta, Ga.; Mrs. Majorie Steitz from Bethesda, Md.; Mr. James W. Autry, Editor of Better Homes and Gardens, Des Moines, Iowa, and Dr. George Gallup, Jr., American Institute of Public Opinion, Princeton, N.J.

Welcome to the committee; delighted to see you all here.

First I would call on Dr. Simonds.

# **STATEMENTS OF ATTITUDES, INFORMATION AND EDUCATION PANEL:**

**SCOTT K. SIMONDS, DR. P.H., PROFESSOR, HEALTH EDUCATION,  
AND DIRECTOR OF HEALTH EDUCATION PROGRAM, UNIVER-  
SITY OF MICHIGAN, SCHOOL OF PUBLIC HEALTH;**

**JOHN FURMAN, BROADCAST STANDARDS, COX BROADCASTING  
CORPORATION, ATLANTA, GA., AND PRESIDENT, GEORGIA  
CHAPTER, EPILEPSY FOUNDATION OF AMERICA;**

**MARJORIE STEITZ, BETHESDA, MD.;**

**JAMES AUTRY, EDITOR-IN-CHIEF, BETTER HOMES AND GAR-  
DENS, DES MOINES, IOWA; AND**

**GEORGE GALLUP, JR., PRESIDENT, AMERICAN INSTITUTE OF  
PUBLIC OPINION**

Dr. SIMONDS. Thank you, Mr. Chairman.

For purposes of brevity at this late hour, I would request that the written testimony submitted would be included in the full record [see p. 112] and by reference the report of the President's Committee on Health Education which I have also supplied to the staff.

Mr. KYROS. Without objection, so ordered, Doctor.

Dr. SIMONDS. Just by way of a few introductory remarks and comments, I should say that the substance of my testimony has been presented, and presented more eloquently than perhaps I could have done it, by the consumer panel and the other members who have testified or will testify in this particular panel.

But I could say that in no other health problem that I have worked in professionally over 25 years in public health education have I found one that has been more difficult or one in which the health education component was more obvious than in the area of epilepsy. And perhaps epilepsy as an educational problem is the most difficult.

It is clear that the stigma, the distorted views and ignorance surrounding the epilepsies continue to create problems for the persons with epilepsy and the communities in which they live.

It is also clear that we have made some progress in attitude changes over the years. But it is also even clearer that much more needs to be done, if we are going to have better employment, less discrimination on the job, less rejection socially, improved case finding and better community health services for the persons with epilepsy.

I would support the formation of a National Commission on Epilepsy, and have suggested in my testimony in written form some possible charges that might be considered.

I think the appointment of a statutory commission on epilepsy could, in itself, be a major educational effort in that it will confirm for the

patient with epilepsy and the community in general, that this is a problem that should be brought into the open, that it deserves a national spotlight, and that it is brought into a framework that can lead to new policies and programs.

If appointed, it would seem to me that the processes used by the commission have the potential for also being educational in nature and making a significant contribution to the change in knowledge, understanding and attitudes which are held by the public, and by the professionals, and by the individuals with epilepsy.

I would hope, therefore, that if the commission is appointed, and I would strongly urge that it be, that the process be one by which the country at large can learn of the significance of this issue and can participate in the planning for the solution of the problem. I think we have seen too many reports filed, and this one is too important to be filed.

Thank you.

[Dr. Simonds' prepared statement follows:]

STATEMENT OF SCOTT K. SIMONDS, DR. P.H., PROFESSOR, HEALTH EDUCATION, AND DIRECTOR OF HEALTH EDUCATION PROGRAM, UNIVERSITY OF MICHIGAN, SCHOOL OF PUBLIC HEALTH

My name is Scott K. Simonds. I am Professor of Health Education and Director of the Health Education Program of the University of Michigan School of Public Health. The Program in Health Education is currently the largest such program in any School of Public Health and trains specialists in public health education at the graduate level. I have served most recently as a member of The President's Committee on Health Education, which studied the problems in health education throughout the United States and presented its report to the President last year. I have served as the President of the Epilepsy Center of Michigan, a state level voluntary organization with extensive services for patients with epilepsy, and as President of the Society for Public Health Education, the major professional organization concerned with public health education in the United States.

As an introduction to my remarks, I would like to enter into the record for purposes of reference for this committee, a copy of The Report of the President's Committee on Health Education.<sup>1</sup> The report describes in broad scope the general problems in health education and recommends action steps at national, state, and local levels. It was clear from the studies carried out by The President's Committee on Health Education that the allocation of resources to the health education field have been seriously neglected at all levels of government. In the voluntary sector there is both fragmentation and duplication in health education. Two major remedial actions were recommended including the development of a National Center for Health Education and the development of a focal point within the Department of Health, Education and Welfare to direct and coordinate health education programs throughout the Department.

As a member of The President's Committee I am pleased personally that the Secretary for Health, Education, and Welfare, through the Under Secretary for Health has taken steps to create these organizations, for without the support and leadership of the Department in health education there will be no sound health education policies and programs at the national level and we will have missed a great opportunity to advance the cause of health through education.

Of all the health conditions or health problems with which I have been associated as a professional health educator over the past 25 years, none has been more difficult to deal with than epilepsy. The problems of the patient with epilepsy are inexorably linked to the knowledge and attitudes of his family and the larger community of which he is a part. The concept the patient with epilepsy has of himself, his abilities, and his potentialities are a product of the interaction between himself, his family, his peers, his teachers, his potential employers, and the community at large. When the attitudes of the public at large

<sup>1</sup> May be found in the committee's file.

and the significant others with whom the patient comes in contact are such as to tell him in effect, that he is not a person of worth or a person with human potential, then he frequently comes to share these views. The valuable contributions of at least four million Americans are frequently diminished as a result of public attitudes.

As long as epilepsy is misunderstood and creates images of irrational human beings in the minds of government officials, police officers, employers, teachers, and the public at large, the individual with this disorder suffers, and in consequence society at large loses the benefits of their being active contributing members of that society. Specifically, individuals with useful skills are not employed where they could use those skills unmaximally. Children in schools are prevented from doing things that other children may do. The list of problems goes on and on.

Through the public health education efforts of such organizations as the Epilepsy Foundation of America and its affiliates, and through selected governmental and some other voluntary agencies, some progress has been made in public understanding and attitudes towards epilepsy. The six major public opinion studies by the American Institute of Public Opinion over the last 25 years, indicate that some ideas about epilepsy held by the public have changed. There is more support now for employing persons with epilepsy than there was 25 years ago. There is more understanding that epilepsy is not a form of insanity, than there was 25 years ago. We find many fewer regional differences in these opinions than we did 25 years ago.

Public health education programs reaching people through local organizations supported and backstopped through state and national organizations, and reinforced through the mass media, particularly the national mass media, have made substantial progress in changing the image of the patient with epilepsy but continued and expanded efforts are needed. The educational programs of these agencies have also made substantial contributions to the public's understanding of the needs for special services for the patient with epilepsy, and this too is an important educational task which needs to be accelerated.

The changes in public opinions and attitudes about epilepsy that we have witnessed over the last 25 years give us hope for the future and the need to have public health education integrated with whatever programs are developed for prevention and control of epilepsy. No national plan for epilepsy can succeed without a public health education component, in my opinion. I would support the formation of a "National Commission on Epilepsy and its Consequences" and would recommend that its charge include at least the following:

- (1) The study, analysis, and documentation of the key public health education problems in epilepsy,
- (2) The evaluation of the effectiveness of current public health education efforts by both voluntary and public sectors,
- (3) The study and analysis of the systems by which public health education programs can be developed and sustained more effectively, and
- (4) The establishment of priorities for public health education, including health education manpower requirements, training of existing personnel in health education methods; development of program models, materials and media; and implementation of evaluative studies that will continually provide new data on ways to improve quality of health education services.

Mr. KYROS. Thank you, Dr. Simonds.

Our next witness is Mr. John D. Furman, from Cox Broadcasting.  
Mr. Furman.

#### STATEMENT OF JOHN D. FURMAN

Mr. FURMAN. Thank you, Mr. Chairman, members of the committee. I am John D. Furman of Atlanta, Ga. I am in charge of broadcast standards at the Cox Broadcasting Corp. I am also president of the Georgia chapter of the Epilepsy Foundation of America.

At the heart of EFA's work is the volunteer effort in local communities throughout the Nation. In Georgia we serve 90,000 people with

epilepsy and a major part of our work is in the area of public health education.

The materials and assistance which we receive from our own national headquarters is, of course, the means on which we build our programs and we sincerely appreciate the caliber of professional help we are given. Other organizations also have educational materials available, but there are very precious few of them. Thus far the load is carried primarily by EFA. However, it is at the local level where much of the information and education work must be done. This is where the people are. This is where we can be of the greatest help in providing for the specific needs of those with epilepsy and the many other segments of the public who need to know more about this disorder. I have attached our Annual Services Report for your review [see p. 116].

For instance, I am familiar with the surveys which indicate the limited extent to which doctors can find time to distribute informational material to their patients. These are very busy men and only 9 percent provide any literature from any source to their patients. And yet, the patient or parent frequently has many, many questions that it would take reams of paper to answer.

Of course, as a broadcaster I am fully aware of the value and the need for national information programs through national television and radio, newspapers, magazines. There are 7,640 radio stations in this country. The cost of producing and supplying just one recorded message to those radio stations can total \$25,000—and this is with the talent provided free of charge. There are some 940 television stations. The comparable cost of producing and supplying one television commercial is about \$21,000. I have heard of governmental support of alcoholism, drug abuse, and others. And I cannot help but feel that similar help is needed on the problems of the epilepsies. This provides a national umbrella over the total information program. But it is up to us locally to see that each segment of the public we serve in our specific area receives the particular information needed. And we have to let them know where to get that information.

I'm aware of the fact that the Federal Government makes literally hundreds of movies. But, I'm personally not aware of any on the epilepsies other than certain highly technical works produced by the National Institute of Neurological Diseases and Stroke.

Can't we find some way to harness the potentialities of the film media to get this story across to people everywhere? We sponsor a number of different activities throughout the State. We cooperate with many local organizations and become involved locally wherever possible. For example, we participated in:

Bike-a-thons, in which as many as 200 riders have participated and widely covered by media;

The sponsorship of an "epilepsy" raft in a famous local raft race down the Chattahoochee River;

The providing of a speaker and films for group meetings;

Attendance at vocational rehabilitation training conferences, et cetera;

Participation in a survey sponsored by the Committee on Health Services of Georgia for the Comprehensive Health Planning Advisory Council;

Attendance at Developmental Disability Executive Committee meetings;

Interviews on radio and the encouragement of articles in newspapers [see attached reprint of a newspaper series which appeared in the Atlanta Journal, p. 120];

The obtaining of John Guthrie, head basketball coach at the University of Georgia and the use of Mr. Guthrie in locally produced television and radio spots;

Public health education meetings held twice a month, open to the general public, and presenting neurologists, psychologists, and pediatricians as speakers.

But, even our best efforts can be improved and multiplied so it is extremely important that a national plan take into account the need of local organizations for both financial and professional assistance in their informational programs.

As you are probably aware, the Developmental Disabilities Act provides for an information and education function at local levels. This is truly a great step forward, for even if services are available, people must know that they are available and where to obtain them. This is the kind of assistance the epilepsy movement could really use. We have to let people know how to cope with the problem, how to live normal, full, productive lives.

As I am sure the public health educators here today would testify, we not only need help in employing more vehicles of communication and getting more messages out with greater frequency, we need to work on methods for determining what happens after the messages are distributed. Is the story getting through? Is it resulting in attitudes and behavioral changes? How do we know? How does this information get fed back into plans of all kinds for the better management of the epilepsies?

Epilepsy is a disorder which can be conquered. We need your help. We need the national plan. It's long overdue.

Thank you.

[Testimony resumes on p. 127.]

[Attachments to Mr. Furman's statement follow:]

ANNUAL SERVICES REPORT

GEORGIA CHAPTER

July 1, 1973 - Present

Information and Referral

Requests for information and literature totaled 3069 during this period compared to 700 requests the preceding year.

Speaking Engagements

In addition, information and educational programs were presented to the following:

Atlanta Area Technical School  
 Atlanta Evaluation Employment Service Center  
 Cobb County Area Technical School  
 Community Friendship Center  
 Crippled Children's Clinic  
 DeKalb Area Technical School for Exceptional Children  
 DeKalb Occupational Educational Center  
 DeKalb-Rockdale Training Center  
 DeKalb Training Center  
 Employment Security(Savannah)  
 Goodwill Industries  
 Goodwill Industries (Savannah)  
 Marietta Vocational School  
 Red Cross  
 Red Cross (Savannah)  
 Robert Shaw Center  
 Salvation Army  
 Seizure Clinic (Savannah)  
 Vocational Rehabilitation (Savannah)

Fulton County Mental Retardation Center  
 Georgia Regional Hospital  
 Greene County Area Mental Health Center  
 South Community Health Center for the Mentally Retarded

John Furman - Attachment I

Briarcliff High School  
 J. J. Daniel Junior High School  
 Fulton High School  
 Myers Junior High School (Savannah)  
 North Augusta High School  
 Northside High School  
 Pennsylvania Street School (Savannah)  
 Riverdale Junior High School

Atlanta College  
 DeKalb Nurses Training School  
 Georgia Baptist Hospital School of Nursing  
 Kennesaw Junior College Health Fair

Family and Children's Services (Savannah)  
 Greensboro Department of Family and Children's Services  
 REACT  
 Traveler's Aid  
 Worth County Department of Family and Children's Services

Savannah Public Information Meetings (15 total)  
 Savannah Unit Symposium (60 Professionals attended)  
 Vocational Rehabilitation Seminar

Alec Shrine Temple (Savannah)  
 Savannah Beach Jaycees  
 Savannah Business and Professional Women's Club  
 Southside Jaycees (Savannah)

The Atlanta Constitution  
 The Atlanta Journal  
 Savannah News  
 Savannah Press  
 WSB-Radio  
 WGST Radio  
 WTOG Radio (Savannah)  
 WZLT Radio (Savannah)  
 WGLA-TV  
 WSB-TV  
 WXIA-TV  
 WTOG-TV  
 WJCL-TV (Savannah)  
 WSAV-TV (Savannah)  
 WTOG-TV (Savannah)

RESULTS OF SERVICES

Emphasis was placed on the following services:

	<u>1973-74</u>	<u>1972-73</u>
Psychological Evaluation	76	35
Follow-Along (Cases carried 90 days or more)	233	192
Information and Referral Services	248	188
Counseling Disabled Individuals and Family	640	341
Transportation for Services	60	14
Personal Care	2	0
Special Living Arrangements	24	27
Identification Bracelets	286	59

The total number of individuals contacted or counseled:

	<u>1973-74</u>	<u>1972-73</u>
Adults	2883	1008
Children	86	113
<hr/>	<hr/>	<hr/>
Total	2969	1121

**Inventory of Services and Facilities Funded Through  
The Epilepsy Foundation of America, Georgia Chapter**

**Information**

**Referral**

**Client Counseling (in office and homebound)**

**Client Employment Counseling**

**Job Placement Supervision**

**Special Living Arrangements**

**Psychological Testing and Evaluation**

**Psychiatric Evaluation and Treatment**

**Psychotherapy**

**Group Motivational Counseling Sessions**

**Emergency Medical Aid**

**Emergency Medical Identification**

**Low Cost Medication Services**

**Agency Seminars**

**Employer Education**

**Educational Counseling**

**Audio Visual Aids**

**John Furman - Attachment IV**

**Exhibit Booklet "Epilepsy" Follows**

**This Attachment.**

# *Epilepsy*

## **The Misunderstood Illness**



**JEAN TYSON** is a native of Anniston, Alabama. She received the B.A. degree from the University of Alabama.

Miss Tyson was a writer for the **AUGUSTA CHRONICLE** for two years prior to joining the **ATLANTA JOURNAL Women's Section** staff in September of 1964.

In 1973, she received the Georgia Conference on Social Welfare Award for outstanding news reporting in the field of Social Welfare. She is also the recipient of the Third Army Recruiting District Public Service Award and the American Cancer Society Fulton County Unit Award.



The Georgia Chapter Epilepsy Foundation of America offers the following services:

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## Epilepsy The Misunderstood Illness

First in a series

By JEAN TYSON

Epilepsy is perhaps the most misunderstood disease known to man. In what has been called the most educated society since the beginning of civilization, a disease that has been around that long, is still viewed with prejudices.

Teachers view the epileptic child as someone who should be in special education, employers are afraid to hire an epileptic — he might have a seizure and disrupt the office — a neighbor won't let her child play with an epileptic child, a parent is too protective and makes the child feel handicapped.

The Epilepsy Foundation's biggest job is education. The Georgia Chapter of the foundation reports there are 90,000 known epileptics in this state. There are more than four million nationally. Eighty per cent of these people are controlled with medication and are capable of being contributing members of society.

Last year the Georgia chapter employed two caseworkers, John McNew and Pamela Starratt. In addition to them, the staff includes a secretary and a fund raiser. There is a branch office in Savannah with one caseworker and a secretary. It is the responsibility of these few people to do whatever they can, with limited funds, to make life a little easier for Georgia's epileptics.

"A large segment of society still thinks epileptics should be in mental hospitals," McNew said. "We bail people out of jail who are there because they had a seizure in public and the police thought they were drunk. This is not the fault of the police. Most epileptics still not wear medical bracelets, which we provide from, stating what their medical disorder is. Alcoholics can go into a seizure of a sort."

"The police who know are good about taking people with seizures to Grady Hospital."

Ms. Starratt said the office here gets calls from people who think epilepsy is contagious.

"We get calls from someone saying another is possessed because he had a seizure. We know of a case where an adult thinks he, and anyone else who drinks from the same glass as an epileptic, will catch it."

"Drugs are another problem. The epileptic is on medication, and there are people who see him taking his medicine and call him a junky."

There are still four states that have laws saying epileptics are to be sterilized. Georgia is not one of these.

"There is the possibility that epilepsy is hereditary," McNew said, "but medically we get away from this. If one parent has epilepsy there is one chance in a 100 that a child of his will have it."

"What people fail to realize is, anyone can become epileptic at any time. A blow to the head will do it. A brain tumor, scar tissue from an old injury, high fever at birth, some diseases of heart and blood vessels, excessive use of alcohol in susceptible people — all of these can cause an individual to start having seizures. A lot of people become epileptic following automobile accidents."

There are many types of seizures, but the



JOHN MCNEW, PAM STARRATT REVIEW CASE

most common four are grand mal, petit mal, psychomotor and focal.

Grand mal is the epileptic convulsion. The arms and legs may make jerking movements, there may be frothing at the mouth and the eyes may roll up. The seizure lasts usually just a few minutes.

The petit mal occur most frequently in children, but adults can have them also. This seizure is usually a brief loss of consciousness and lasts only a few seconds. The person having this type of seizure usually has a blank stare and appears to be daydreaming. Petit mal seizure can occur several times a day.

Psychomotor seizures cause a person to do things such as pick at his clothes, open and close a file drawer over and over, make chewing movements. The seizures can often be prolonged, and are often confused with psychiatric disorders.

There are many different types of focal seizures. Consciousness may not be lost when the seizure remains limited to one area. These can spread to all parts of the body and lead to a grand mal.

Focal motor seizure consists of jerking movements or stiffening of the muscles of one part of the body. This could be momentary or last several minutes.

Focal sensory seizures produce sensations such as numbness, tingling or heaviness in one part of the body. This could spread to include other parts of the body and become a focal motor seizure.

"Some epileptics," McNew said, "have an aura connected with their seizure and know when one is going to occur. This is generally

# Most Can Lead Useful Lives

with the grand mal and usually happens to people who aren't on medication. These people may have a strange sensation, or they may smell an odor, or see flashing lights.

"Many with grand mal seizures who are on medication know when they are going to have a seizure and can sit down."

Ms. Starratt said most epileptics can return to work following a seizure.

"He may need to rest for an half hour, but he can continue to work afterward."

"People don't know what to do when they see someone having a seizure. The best thing to do is nothing. Leave the person alone."

"Some people want to put a spoon in the person's mouth. This will break his teeth. Medically you can't swallow your tongue. If you bite it off, it is the one organ in the body that reproduces itself."

"If a person falls down with a seizure, you can try to keep him from hurting himself by moving objects out of his way. You might turn his head to the side if possible, and if he looks like he is having trouble breathing, keep his head turned up. Beyond this, don't do anything."

"Don't call an ambulance. There is nothing anyone can do during the seizure. If the person goes from one seizure to another, then call an ambulance, but this is the only time."

"When a person is having a seizure, he isn't violent and he isn't going to smother. It may look awful and sound terrible, but the individual isn't in pain and he isn't going to hurt you."

Because of discrimination in employment, there are some epileptics who do not tell their employers. When a seizure occurs on the job, the employee is fired.

"There is a problem in the area of liability for the employer," McNew said. "Workmen's compensation covers anybody who works in the state. A problem does come if an individual suffers seizures, even when on medication, and hurts someone else. This could happen if the epileptic works with machinery or on things such as ladders."

"Accident and life insurance is hard for them to get. Some companies will insure them, but the premiums are high, and therefore a lot of epileptics don't have any insurance."

If an epileptic doesn't tell his employer about his condition and the employer finds out, this is fraud and grounds for dismissal. This is why we ask these people to come to us. Let us handle with the employers. We can make all the innuendos for them. We also handle job discrimination cases against epileptics."

"My job is to talk to employers and convince them they should hire epileptics. They make as good or as bad employees as any one else."

"Once I can get in to talk to an employer, I have little trouble placing an individual who can do the job. I do a follow up for 90 days. I call the employer once a week, do on the job observation and see how the person is doing. After three months if there are no problems, the employee should be on his own and hopefully our agency will not see him again."

Mauday in the The Atlanta Journal-Woman's Section: Problems parents of epileptic children face.

Second in a Series

By JEAN TYSON

There are more than four million epileptics in the United States. This is eight times the number of people reported to have multiple sclerosis, and more than double the number of people reported to be under treatment for cancer.

People don't view the person with either one of these illnesses as someone to be frightened of. Yet people fear the epileptic simply because most people don't know enough about the illness to accept it.

Children, as well as adults, suffer from epilepsy. Treatment by other adults and classmates often causes psychological problems in children with the illness that also have to be dealt with.

While 80 per cent of the known epileptics can have productive lives when controlled by medication, there are 20 per cent that can't be controlled.

Mrs. Stephen Weierman's son, Scott, falls in the 20 per cent group.

Scott, who is 14, had his first active seizure when he was 12.

"He is a complete epileptic," Mrs. Weierman said. "Most people have one type of seizure or the other, but he has four types, and has 30 to 40 seizures a month."

"While Scott is on an exception, he is by no means a rarity. There just aren't easy places to get the type of help we need. There is one school for the severe epileptic that is sponsored by the National Epilepsy Foundation. This school gets over 400 applications a year, and only 62 students are taken."

"Scott is in the school now, and will be there for two years at the most."

"I carry a load of guilt because I brought him into the world. I feel responsible for his epilepsy."

"We don't turn to the Epilepsy Foundation for help until this year, but we did for help for the family as well. Whenever there is an individual in a family with a problem, the family has a problem also."

"We have a 19-year-old son who is worried about the future. He already feels the weight of having to take care of Scott when we die. It isn't pleasant for a young man to have to face the future with this weight around his neck. We also worry about what will happen to Scott."

"This also has been a terrible strain on our marriage. When Scott is home, I can't go grocery shopping or to the neighbors for a cup of coffee. He has to have constant care. This is a terrible way to put it, but it is almost like being in jail."

"Talk about prejudice. I know all about prejudice. I have seen Scott ostracized, mothers not let their children play with him, teachers not wanting him in school. He got into a terrible emotional state because of the treatment he received from other people."

"He has become an angry young man, and I don't blame him. There are so many ignorant people around. We have the best educated generation in our history, and people are ignorant about something that has been around since medieval times."

"The schools are teaching everything from birth control to drug abuse, but the schools refuse to teach anything about epilepsy."

"People aren't prejudiced about people with heart trouble. People say hire the handicapped, but they mean the physically handicapped."

"For the 80 per cent that are controlled and can live normal, productive lives, I can't understand why there is any prejudice, but there is."

"We are in the military and have lived all over this country and the world. The situation isn't all that different anywhere you go. Why should Scott be denied an education and a chance for a full life? It is never retarded as he could get all sorts of help."

"We take care of everyone in this country, but we let these children live in their own little hell, and that is what they live in — a little hell."

"I guess God sends these children to people who will love them. What would happen if he sent them to people who didn't?"

"The foundation helps as much as it can, but they are limited in what they can do because they don't have the funds. Nobody will give in the Epilepsy Foundation like they do to other places."

"I am not afraid to admit my son is an epileptic. I don't believe by hiding it you help anybody."

Mrs. J. C. Causey's 7-year-old son Patrick is on the other end of the spectrum. He developed epilepsy two weeks before he started the first grade.

"He had chicken pox," Mrs. Causey said. "We don't know if the chicken pox caused it, or just brought it out, but both happened at the same time."

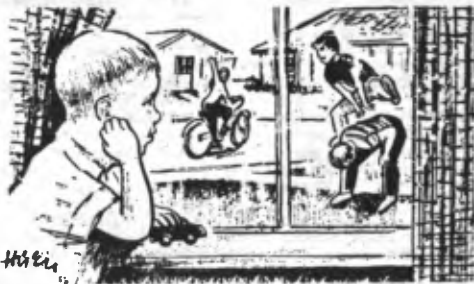
"He has grand mal seizures and is on medication. So far he hasn't had a seizure at school. So far everybody has been nice to him and to me. Of course the first six years of his life he didn't have any seizures and had made friends."

Mrs. Causey said she did visit with Patrick's teacher and wasn't sure how the teacher reacted.

"She sort of acted indiffer-

# Children Suffer Also

## More Have Epilepsy Than Multiple Sclerosis



ent. I don't know if she is really hard about epilepsy and was just tired of hearing about it, or if she just didn't care."

"I didn't know anything about epilepsy when my son started having seizures. I was really horrified and sick because I didn't understand what was happening to him."

"But now I can see why the doctor said a brain tumor was worse and that Patrick could have something worse than epilepsy. He also said he could outgrow it — some do."

Mrs. J. C. Causey who is in her early 20s didn't start having seizures until she was 14. The cause hasn't been determined.

"She is controlled with medication, but epilepsy has been a problem for her. Her doctor recommended she not take the college preparatory course in high school. He felt college would be too much for her, so she took the general course."

"She had friends where we used to live and she used to go back and visit a lot. We moved here several years ago, but she was neglected somehow."

"She used to have grand mal seizures, but now she has the type that affects her left arm, face and arm. She is never sure when one will occur."

"She applied for a job at two stores in a shopping center, but we never heard anything at all from the stores. The application blanks asked for illness and what type of medication she was taking."

"We got a notice from the

Epilepsy Foundation of Georgia, and we called them and asked for help. They have been really sure to help us, and have gotten her enrolled in an evaluation program to detect what she can do. She seems to enjoy this and is going every day. She has even made some friends."

"I had never had any contact with epilepsy and when this happened, it hit me like a bolt of lightning. Our second child was only 8 months old at the time. She is a mongoloid. We had just gotten used to this when our older daughter started having seizures, so we had a double blow. But I guess the Lord gives you what you can take."

Mrs. K. also has a daughter in her early 20s who has epilepsy.

"She had a stroke when she was 17 months old," Mrs. K. said. "This is itself is unusual. It is believed her epilepsy grew out of this. I told the doctor what was wrong with her. I knew something about epilepsy and she started gritting her teeth and blinking her eyes, I knew what it was. The doctor said she was just going through a phase."

"She went to public school until the 11th grade, but she got all these emotional problems because of the way people treated her. She has a terrible time coping with any sort of relationship."

"When she meets new people, she wants them to know. She worries about having a seizure. People don't understand and they are frightened. Most people act like they don't know anything about it

They have said they saw somebody have a fit — a word I hate."

"People act like she hasn't tried to do anything, but she has. She has had evaluations until she is tired of them. She has never had any opportunity or anything offered to her."

"Perhaps she will go for a week without a seizure, and then she will have five or six in one day. When we lived in another state she worked at Goodwill and she only had seizures on the weekends — never at work. I think this was because she was over-tired."

"It is something I can understand and I don't know why other people can't. People are so ignorant. Epileptics are better off than a lot of people — people with high blood pressure or diabetes. Epilepsy isn't going to kill you."

"Even my family has been a problem. She has to take a lot of medication and sleeps a lot. Some of my family has said it is foolish for her to take medication. Others say I spend her too much and others treat her like she will die any minute."

"I have read everything there is to read about epilepsy and I get real discouraged. It is a lonely life and I just live from day to day."

Tuesday is the Atlanta Journal Women's Section: Epilepsy in the Schools.

# He Can Still Do School Work

Third in a series

By JEAN TYSON

A child with epilepsy isn't any dumber or smarter than any other student. His misunderstood illness has nothing to do with his ability to function in the classroom, which is where he belongs.

The National Epilepsy Foundation estimates that about one in 50 children has epilepsy. However because of a lack of understanding, many educators feel the epileptic student belongs in special education. A seizure may disrupt the classroom and frighten the other students and the teacher.

Just because someone is an epileptic doesn't mean he is going to suddenly fall down and start shaking and jerking movements all over the floor.

It is often in the classroom that an enlightened teacher has the first clue that one of the students has epilepsy.

Symptoms that a student may have the illness include staring or daydreaming, tic-like movement, rhythmic movements of the head, purposeless sounds and body movements, head dropping, lack of response, eyes rolling upward and chewing and swallowing movements.

If a teacher notices two or more of these symptoms in a student, she should consult the school health nurse. Only after a thorough examination can it be determined if a student is an epileptic.

Rose Anne Mullinax, with the DeKalb County School system arranged for an Inservice program for the faculty at the occupational center where she works. Students attend a regular high school part of the day and the center the other part.

"The Georgia Chapter of the Epilepsy Foundation arranged for Pam Starratt to come out and give a program on epilepsy for the faculty.

"We have two students here that we know are epileptic. One we have known about, but

## *Epilepsy* The Misunderstood Illness

the other we didn't until we had this program.

"Afterwards one of the instructors said he thought one of his students must be having seizures. As it turned out the student was having seizures at school. It wasn't the grand mal type, but a repetition of motion.

"We called his high school and learned that he did act strange sometimes, but no one really paid any attention to him.

"We called his family and his parents said they didn't know. The boy is now on medication. If it hadn't been for this program and the instructor recognizing what was happening to the student, he wouldn't have gotten help.

"After this happened I wanted to do some counseling in small groups and inform the students about what was happening so they would have a better understanding of the illness.

"However, the parents requested we do nothing, and in a case like this, the parents are the law. It seemed to me the other kids were making fun of this boy because they didn't understand what was happening to him. But this is something he will have to live through.

"I feel this high school group is a good one to get the information to.

"It is a frightening experience for anyone, and from a teacher's point of view it is frightening even if she is prepared.

"My advice to parents is, if you know your child has epilepsy, talk to your child's teacher or teachers, not just the school counselor. Talk on a one-to-one basis with the teacher. If the student is old

enough, include him in the discussion. This would be very helpful to a teacher.

The best thing a doctor told me, was to leave the student alone when he is having a seizure. Some teachers fear the student will die and wonder what will happen to her if he does. You don't die from a seizure, but some teachers do not know this.

"As far as ability to achieve or take instruction, these students are not any different from any other student. Some are at the bottom of the ladder and some are at the top."

Ralph Matthews, a seventh grade counselor at another school, said his school hasn't done anything other than inform the teachers and make them aware of the students who do have seizures.

"We try to prepare our teachers as much as possible, but you can't really prepare anyone for a crisis situation. We have talked with the principal about having someone from the Epilepsy Foundation give us an inservice program on epilepsy. He does not object to the idea, but we haven't scheduled the program yet.

"We have two students that we know about who are epileptic. We have talked with their teachers and made them aware of what to do if the students have seizures or appear to not be functioning normally in the classroom.

"One had a seizure in the lunchroom and there was quite an audience. The other students were mostly very curious, and I am sure they were concerned for his well being.

"This is something you don't see every day and since it is not a common occurrence, you don't fully comprehend it.

"Yet some experience is often the better learning method. I'm sure for most of the students this was the first time they had seen someone have a seizure.

"We try to prepare ourselves, not only for cases of emergency, but to better understand the youngster and to watch for emotional instability that often goes along with this.

"I was concerned if one of the students was getting the proper treatment. His attendance was off and with my limited knowledge, it was my understanding that an epileptic was supposed to live a normal life. This boy didn't appear to be living normally.

"In the back of my mind I remembered the Epilepsy Foundation and called for help. I was impressed with how interested the people there were in my case. They talked to me, the student and the parents immediately. We learned the boy is receiving proper medication, but has other problems that were causing his absence from school."

The Atlanta Evaluation Employment Service Center is for anyone who has any type of handicap and is seeking employment.

Lela Long, a rehabilitation counselor at the center, said the person doesn't have to have a physical disability.

Wednesday in The Atlanta Journal Women's Section: One epileptic who lives a normal life.

'I am a functioning person in society. I hold a full time and a part-time job and I go to school. My epilepsy has nothing to do with my ability to lead a normal life. I don't think I am different from anyone else.'



Staff Photo—Al Stephenson

Diane Burnett Checks Patient's X-rays

## She Had Her First Seizure at 21

Fourth in a series

By JEAN TYSON

Diane Burnett is one of the 90,000 known epileptics in Georgia. She, unlike many who suffer from the illness, has felt no prejudice or discrimination. She is employed full time as a radiological technician in an orthopedic surgeon's office, works weekends at West Paces Ferry Hospital and takes eight classes in psychology at Georgia State University.

If she didn't tell you, you wouldn't know she has epilepsy. Not every epileptic has convulsions and not every epileptic is born with the illness—in fact most aren't.

"I never had a seizure until I was 21, and then I didn't know that was what I had. I was working in Florida, when a doctor called for a report. I was reading it to him over the telephone when all of a sudden I couldn't pronounce the words.

"I started spelling them to him. You usually spell in syllables, but I was spelling one letter at a time.

"I had a friend who was a general practitioner and I mentioned this to him. He suggested I get a lateral skull X-ray thinking I had a tumor. Nothing was found.

"He referred me to a neurologist and I had an EEG and an examination. The doctor asked me if when I had a seizure did I feel as if I were on the ceiling looking down at myself. I didn't know the connotation of what he asked and what was wrong with me. I told him no.

"Then he wanted to know if I had hit my head. I said not to my knowledge. I told my sister about this and she remembered that I was hit in the head with a bat when I was a kid.

"The doctor suggested I take Dilantin, but I said no because I thought it was a tranquilizer. It was explained to me that it is an anticonvulsant, so I take it.

"I have petit mal seizures. I don't lose consciousness or touch with reality. I know everything that is going on around me. The only thing that happens is I can't pro-

nounce words, and it is frustrating.

"If I'm reading a book and this happens, I just put it down until it passes. I am always amazed when I get back to reading to see how clear everything is. It is sort of like when you are real tired and you read the same line over and over trying to get the meaning.

"This doesn't prevent me from driving. The only thing that could happen is, I could pass the expressway exit I want because of reading the sign slowly. But I can recognize the shape of the usual highway signs such as the stop ones."

Ms. Burnett said her employer is aware of her epilepsy and writes her prescriptions.

"I have insurance through the office, but one insurance company refused to insure me because of my epilepsy. When the report came back to the agent who handles our insurance, he put it through another company and I am insured. There is a rider at-

tached that says I have epilepsy and the premium is 160 per cent higher than for other employees, but my employer pays it.

"Insurance companies don't understand medicine. They have a surface knowledge of medicine, but no experience.

"I have suffered no discrimination because of this. I think people are discriminatory anyway. We discriminate because of the way someone wears her hair, or the way someone lives.

"I am a functioning person in society. I hold a full time and a part-time job and I go to school. My epilepsy has nothing to do with my ability to lead a normal life. I don't think I am different from anyone else."

Thursday Is The Atlanta Journal Women's Section: Employers who hire epileptics.

# Employment Is Often A Problem

*Last in a series*

By JEAN TYSON

John McNew, a caseworker with the Georgia Chapter of the National Epilepsy Foundation sent out 1,000 postcards to prospective employers in Georgia asking each to check one of three blocks, and mail back to the foundation. The return card was pre-addressed and postage was prepaid.

The employer was to check "I would consider hiring an epileptic," "I would like to have more information," or "I cannot consider it at this time."

Only 10 employers returned the cards. Of this seven were willing to talk about employing the epileptic, one said no, and the other two wanted more information.

The misunderstanding of so illness that has been around since the beginning of civilization continues into today's society. Men who have made significant places for themselves to history also suffered from epilepsy. Some of these were Alexander the Great, Napoleon, Sir Walter Scott, Lord Byron, Caesar, Dante, Tolstoy, Beethoven, Charles Dickens, Vincent Van Gogh and Socrates.

"There is no reason why most people with epilepsy can't be employed," McNew said. "Eighty per cent of the epileptics are controlled with medication, and can be contributing members of society."

"I was disappointed at the number of postcards that were returned."

McNew's job is to call on employers, explain what epilepsy is and ask firms to give one or more persons who suffer from the illness, a chance. He has found that once he can talk to an employer, he can get a job for an epileptic who is qualified.

"I was running an ad for employees when John McNew contacted me," said Jim McBee, manager of a company that produces records. "He laid it right on the line. He said some of them would make good employees and some would not."

"The girl we have now hasn't missed a day since she started in December. In comparison to the rest of the people, that is good. She is here on time, does a good job, follows instructions and is interested in her job."

"I'm just as happy as I can be with her. I'll take all the people like her I can get. These people have the same right to a living as everybody else. If they do a good job here, they have a job. If they don't, they are out."

"There is a possibility she will have a seizure on the job. I asked her what should I do if she has one and she said she would sit down. I could care less if she sits on the floor. Nobody around here would think anything about it."

Matt Moore, personnel manager for a company, said his company had an epileptic and didn't know it until he had a seizure on the job.

"I didn't realize he was an epileptic and neither did the company. He had a seizure at work. We sent him to the company doctor. His problem was he thought he had stopped having seizures and be stopped taking his medicine."

"Why should we get rid of a good man just because he had a seizure? It is ridiculous to take a person and train him for three or six months, and then find out he is an epileptic and let him go."

"We did move him out of the department he was in to another one so he wouldn't get hurt. The department he is in now gives him more opportunity for advancement."

"I think our insurance company would take a dim view if we left him in a department where he could hurt himself."

"I don't know if there are others working for us or not, but if so, I wish they would come forward. We will find a place for them in the company, if they are in an area where they could get hurt."

"This is like any other illness — like me getting hay fever every spring. That doesn't stop me from working."

John Spoto, manager of a company, said he has an employee sent to him by the Epilepsy Foundation.

"I wasn't in this job at the time, but I was consulted about him. I have nothing against it. He has seizures on the job and he knows how to handle himself. I keep pills for him in my desk, and when he thinks he is going to have a seizure he comes and tells me. I give him a pill and let him lie down."

"Sometimes you have to handle an epileptic a little differently. Sometimes if you holler at them, they will get excited and this could cause seizures."

Gary Brown, accounting department manager for an insurance company, hired an epileptic on his staff last September.

"We will interview anyone who wants to apply for a job here," Brown said. "When he came in we were interested in his insurance background. He had an accounting background, so we hired him on that basis and he is continuing to learn along with all of us."

"We hire people on the basis of their capabilities, not their illnesses. In this case, we did talk to his doctor to see what medication he is on and if he is stabilized."

"We carry our own hospitalization and he is a part of our plan. He had a mild seizure about two weeks after he came here."

"I feel an epileptic needs as much of a chance as anyone else."

Chuck Davis with the Internal Revenue Service said the government has a program to hire the handicapped.

"A mso we have working here stated on his application he was an epileptic," Davis said. "I hired him. I used to be a school teacher and had children in my classroom who were. Once you know what it is, there is no reason for concern."

"It is just a matter of education. This illness is no more severe than some others. The person with epilepsy has the problem, no one else does. It is nothing to be afraid of. You aren't going to get hurt."

"We don't screen for epilepsy. As far as the government is concerned, it isn't a problem."

**Epilepsy**  
The Misunderstood Illness

Mr. KYROS. Thank you, Mr. Furman.

Our next witness will be Mrs. Marjorie Steitz from Bethesda, Md. Mrs. Steitz, welcome to the committee.

### STATEMENT OF MARJORIE STEITZ

Mrs. STEITZ. Thank you, Mr. Chairman.

I am Marjorie Steitz, professional writer, wife, and mother. I live in Bethesda, Md. By way of further introduction, an article I wrote, entitled "Epilepsy: Why the Secrecy and Shame," was published nationally in Sunday newspapers by Metropolitan Newspaper Group, reaching an estimated 6 million readers. It won for me and for Metro the 1973 Journalism Award of the Epilepsy Foundation of America.

The first time I ever heard of epilepsy was when, as a college graduate, a wife, and a mother, I read about it in a comic strip, Rex Morgan, M.D. This was some 20 years ago.

If I could live to be an adult without knowing anything about it, there must be millions like me.

One of the important things I have learned recently about epilepsy is the large degree of public ignorance about this disorder, and to this I will address my remarks this afternoon.

My next encounter with epilepsy occurred a couple of years ago, when my husband and I had learned that one of our five children, who was 11 then, was seizure prone.

Had it not been for my blurred memory of that old serial comic strip I might not have had the sense to take him to a pediatrician for diagnosis, but we did get help, and it was very good help.

Our doctor asked us a number of questions, took tests, started medication, and the prognosis is very good. Since our doctor's attitude was very matter of fact, and he wasn't alarmed, we weren't either.

Well, our son is doing very well, and the prognosis is good for many other youngsters who take their medication faithfully, who get medication promptly, and gain control over their seizures.

And his attitude is good, too, thanks in part to friends and neighbors and teachers who have casually accepted his disorder.

I decided to write a story about our experience, hoping it might light a very small candle for other parents.

In the process of writing the article, I came into contact with many people for whom an appalling information gap exists on the subject of epilepsy. I would like to very briefly tell you about just a few of them.

First, a visit to the seizure clinic at Children's Hospital here in Washington, D.C. I talked to a Spanish-speaking mother with two children, Carlos and Maria, aged 3 and 5. Maria was fine, but Carlos was seizure prone. Their mother told a sad tale of being called to their nursery school, seeing a crowd and an ambulance, and Carlos lying on the floor.

The teacher, very upset, told her to take Carlos home and never bring him back. Since he and his older sister were inseparable, the older sister stayed close by to make sure he never fell in the street when having a seizure.

This meant that Maria had to drop out of school, too, and the two children had nothing to do all day. If only the teacher had known.

I talked to a neighbor—we will call her Carol—who twice had rushed her 2-year-old to the emergency ward of a nearby hospital when the child had seizures, and by the time they got there, of course, the seizures were over.

Her doctor simply said to her, "Well, if it happens again, give me a call." She was confused and terrified. If only her doctor had taken the time.

A mother in a well-to-do residential neighborhood told me of her very own friends and neighbors behaving much the same way—in horror—when her son, whom they all knew, had a seizure a block from home. They just stared as he banged his head on the pavement.

Even in print one sees incredible information gaps.

Last year a crooner was quoted in a national magazine as saying epilepsy is the work of the devil.

A well-known writer depicted epilepsy in the most sensational blood-curdling way in order to sell his popular novel.

Now, later, both the crooner and the writer apologized and retracted their statements but the damage had already been done.

People like this who mold public opinion must be educated also.

Well, my story appeared, and I started getting a lot of mail. I would like to quote one excerpt for you. This was from a New York News reader:

I have about six seizures a year, but you get to know what to do. The aura.

I remember one night on the Long Island Railroad, a very crowded train, I was standing but I just couldn't get to the men's room. Five minutes later I came too. (I don't fall.) Do you know I sat down, people just wanted to get away. I told the conductor, too much liquid for lunch, and we both laughed.

In other words, in our society it's all right to be drunk, that's understandable, but not epileptic.

While research for and response to my article reveals serious information gaps on the subject, I am encouraged, as I think all of us should be, by Mr. George Gallup's recent findings, which have been mentioned here today.

Prejudice and ignorance are diminishing slowly. Yet his figures, as well as my own experience, tell me that the information gap among other parents on the subject of epilepsy rests most among those who are least educated, least skilled, and least trained. We must reach these people.

I am pleased my article appeared in the New York News, rather than the New York Times, for this reason. But I would like to see further articles in many publications, and of course on TV, too.

We must carefully target our audiences on the basis of known research facts provided by Dr. Gallup and others. We must have an overall information spreading plan, a plan recognizing specific groups who need to learn, and a plan of what to say to them once we reach them.

You can't talk to the mother of Maria and Carlos, the teacher of Maria and Carlos, and a practicing physician all in the same way and through the same communication.

I hope I have illustrated the need to reach them all. The passage of your bill, Mr. Kyros, could pave the way for an overall plan to reach them.

Thank you for this opportunity to appear before you on behalf of parents of millions of children with epilepsy.

[Testimony resumes on p. 134.]

[Mrs. Steitz' prepared statement and attachment follows.]

STATEMENT OF MARJORIE STEITZ, BETHESDA, MD.

I am Marjorie Steitz, professional writer, wife and mother. I live in Bethesda, Maryland. An article I wrote, entitled "Epilepsy: Why the Secrecy and Shame" was published nationally in Sunday newspapers by Metropolitan Newspaper Group, reaching an estimated 6 million readers. It won for me and for Metro a Journalism Award.

The first time I ever heard of epilepsy was when, as a college graduate, a wife and a mother, I read about it in the funny papers. That was some twenty years ago. With all that I have learned about epilepsy in the past two years, I find this amazing. And yet, one of the important things I have learned recently is the large role of public ignorance about the disorder. If I could have lived to be an adult without knowing anything about epilepsy, there must be millions like me, who knew nothing about epilepsy until they read something, or until they knew someone afflicted with it.

And if my initial information came from a comic strip read by 15,000,000 people, many others must have had epilepsy introduced to them by "Rex Morgan, M.D.," too. I hope so, for it was an excellent episode, describing the frustration for a seizure-prone young woman in finding a job. Even though her seizures were controlled through medication, she met fear and prejudice among potential employers.

My next encounter with epilepsy occurred a couple of years ago, when my husband and I received the news that one of our five children, who was eleven years old then, was seizure-prone. Had it not been for my blurred memory of that ancient comic strip story, with its description of a seizure, I might not have had the sense to take our son to our pediatrician after his second seizure, to find out what was wrong. I might have thought that his particular behavior, waking up in the night, was just a bad nightmare.

As a matter of fact, that is what I thought, the first time. When he had a second nightmare a few nights later, I knew something abnormal had happened. I still mulled it over a day before I took him into the doctor. Why? Dr. Cereghino of NINDS tells me this is often a parental first reaction—rejection of the fact—the fact of epilepsy in their child. "If I ignore it, it won't exist."

But we did get help, and learned a lot too. Our pediatrician started off asking use a number of questions about the "nightmares," and remarked he felt there were sufficient symptoms of a seizure pattern to warrant taking some tests, including lab tests and an EEG at a nearby hospital, and starting some medication. Our doctor's attitude was calm and matter-of-fact, and since he was not alarmed, we weren't either. In ensuing visits, he unhurriedly answered all our questions (sometimes asked repeatedly, because we couldn't encompass everything at once), and explained to us a great deal about seizure patterns. He never used the word epilepsy, because he said it is just too emotional a word. "If you tell a parent his child has epilepsy, he hears nothing more you say. He is in a state of shock."

The prognosis for our son is good, as it is for so many, many youngsters who are put on medication promptly, take their medication faithfully, and gain control over their seizures. His attitude is good, too—thanks in part to the friends and neighbors and teachers who have taken a view of casual acceptance of his disorder.

It isn't always so.

Now that we know what our boy has, and have mentioned it around, we find lots and lots of people we know have seizure patterns or have relatives who do. Once we share with them our experience, their story comes out. Unfortunately, not everyone has had the sensitive medical advice and community acceptance we received.

As I learned more and more about the social manifestations of epilepsy for parents and their afflicted children, I decided to write a story about our experience, hoping it would light a very small candle for other parents. I might save them some of the fear and confusion we had known, and might alert them to

some of the prejudice we had heard about. In the process of writing the article, I came into contact with many groups of people for whom an appalling information gap exists on the subject of epilepsy. I would like to tell you about just a few of them—briefly.

First, a visit to the seizure clinic at Children's Hospital in Washington, D.C., where there is trash blowing in the streets, but where there is the same dedication to the problems of people with epilepsy that one encounters amid the beautifully landscaped lawns of "the reservation" at NINDS. People line up to receive excellent medical care, and I talked to many mothers of the inner city about their problems as parents of seizure-prone children. (The neurology staff of the hospital granted me permission to interview mothers and children on the condition, of course, that they agreed to it and that all identities were protected. So my names are fictional.)

I talked to a Spanish mother with two children, Carlos and Maria, aged 3 and 5. Maria was fine, but Carlos had been coming to the seizure clinic ever since he was eleven months old, when he had his first seizure. He was on medication, and the seizures will probably be controlled, but his mother told a sad tale.

"No, Carlos and Maria do not go to school now. They are home all day with me, now. They liked nursery school, but one day the teacher called me to come right away, very excited. When I got there, there was an ambulance outside, a big crowd, much yelling. Carlos was lying on the floor of the school. They told me his limbs had moved all over, there were bubbles in his mouth. I took him and Maria home and the teacher said never bring him back. Very excited. Months after, the owner of the school called me. She was angry with the teacher and said bring Carlos back. But by then Maria was five, and they said she was too old to come back; she had to go to kindergarten. These two have always been so close—Maria watches him every minute to see he does not have an attack and fall in the street. I will keep them together. If she cannot go to his school, he will not go. He does not want to go back anyway. It is a big problem; this thing. They have no place to play, no place to go all day."

If only the teacher had known \* \* \*

I talked with a neighbor, call her Carol, who twice took her 2 year old daughter, Joyce, suffering repeated seizures, to the emergency room of a local hospital right in the shadow of NINDS. By the time, terror-stricken and shaken, she rushed in to have Joyce examined, the seizures were over. Each time she was told simply to go home and give the child an aspirin and call her family physician in the morning. Each time, her doctor said, "Well, if it should happen again, bring Joyce in \* \* \* ." The mother was near hysterics of concern and confusion when I talked to her.

If only some doctor had taken the time \* \* \*

Then there is the scene I witnessed at a large stadium of a man having a seizure—and the crowd shrinking away from him in horror. No one went forward to help him as he fell on the cement steps. They just stared.

A mother in a well-to-do residential area told me of her very own friends and neighbors behaving much the same way when her son—whom they all knew—had a seizure a block from home. They called her, and she arrived upon the scene to see them standing around staring in horror at her son as he banged his head on the pavement.

Even in print one sees incredible information gaps. Last year a crooner was quoted in a national magazine as saying epilepsy is the work of the devil. A well-known writer depicted epilepsy in the most sensational blood-curdling way in order to sell his popular novel. Both the crooner and the author later apologized and retracted their statements—at the insistence of EFA and others—but of course the damage was done. Better no information than that kind of mention.

When I finished my story, I took it to Metropolitan Sunday Newspapers, one of whose editors was particularly eager to run a public information story on epilepsy, and he told me why. He will never forget when he first moved to New York City and witnessed the death of an infant in the apartment next door. The child had a seizure—the parents, panicky, put the child's head in a gas oven, thinking a little gas might "calm him down."

If only they had known \* \* \*

Well, my story appeared. The mail poured in, and some of it was heart rending, some inspiring, and some from quacks. If ever a theme emerged, it was the need for dissemination of information. I would like to share with you just a few excerpts from these letters.

This is from a Franciscan friar. "I have had epilepsy for about 16 years—since about the age of 14. I was delighted with your article because it has been just recently that I have become convinced of the need for anyone with epilepsy to get over the fear of risking exposure. It is only in this way that we will come to help others—perhaps far more than we can imagine."

And this from a man who read the story in the New York News while riding the subway:

"Your story was good and it may help a little. I'm not a child like your son; I was 38 years old, 21 years ago, with a family, when my condition happened. My position at the office has not changed since—no promotions. With a couple of years to go, it doesn't matter now.

"I have about six seizures a year but you get to know what to do. The aura. I lock my office door, or go to the stall in the men's room. I know every exit stairwell. Sure these are dangerous tactics but don't let anyone kid you the risk is better than the talk, or gossip. I remember one night on the LIRR, a very crowded train, I was standing but I just couldn't get to the men's room. Five minutes later I came to. (I don't fall.) Do you know, I sat down, people just wanted to get away. I told the conductor, too much liquid for lunch, we both laughed.

"Well known people do not want to admit to having E. This fact alone is to tell you just how public opinion regards the disease. A dope addict is regarded in a better esteem.

"My time for work is over soon so I really regard it all philosophically. For your son, I would tell him keep the chin high and proud. For you, keep writing. It's a long, hard fight."

While research for and response to my writing on epilepsy reveals serious information gaps on the subject, I am encouraged, as I think all of us should be, by Dr. Gallup's findings in a number of surveys he has published between 1949 and most recently, on May 16 of this year. As a parent of a child afflicted with epilepsy of course I am very pleased to see that only 5 percent of other parents, now, according to the Gallup Poll, would object to having their children in school or at play with my son, opposed to some 24 percent, or almost a quarter of the adult population, surveyed by Dr. Gallup a quarter century ago.

Yet, looking at some of Dr. Gallup's earlier findings in this series of surveys on public attitudes toward epilepsy, I am impressed by certain patterns I imagine he will cover before this Committee in expert detail. Using the same question in 1969—"Would you object to having any of your children in school or at play associated with persons who sometimes had seizures"—the Gallup Poll found marked differences in answer by groups.

By education of respondents, for instance, 92 percent of college graduates answered "no." In contrast, only 66 percent of American adults with a grade school education replied in the same way. Similarly, we see 91 percent of those with families engaged in professional and business activities replying "no" to the question; contrasted to only 71 percent saying they would have no objection to their children playing with my son, who are themselves manual workers or adult family members in this category.

These figures, as well as my own experience, tell me that the information gap among other parents on the subject of epilepsy rests most among those who are the least educated, those who work with their hands. So I am pleased that my article appeared in New York in *The New York News* rather than *The New York Times* . . . but I'd like to see further articles in many publications, and on TV too.

In short, I think we can close the remaining communications gap among parents on epilepsy through the extensive dissemination of information, but only if we carefully target our audiences on the basis of known research facts provided by Dr. Gallup and others. By this I mean that I plan to continue my writing on epilepsy for the popular press, as does Ann Landers, who has done so much, and Dr. Nicholas P. Dallis, better known as the creator of "*Recs Morgan, M.D.*" I'd like to close with an excerpt from a recent letter from Dr. Dallis, psychiatrist as well as comic strip creator:

"Interestingly, the morning your story arrived, I was playing golf with some friends. During lunch, after the game, the one man said that he wanted a free consultation. It seemed that he had just taken on a new salesman in his small software computer firm. The new employee had been with him for about a week, came to him with excellent references as a salesman.

"My friend went on to explain that he had been spending a good deal of time with the man, orienting him about their product, etc. But there was one thing which was starting to disturb him about the new salesman. He had a great enthusiasm but every so often, right in the midst of an animated conversation, he would seem to be unaware of anything for a matter of a few seconds. And, strangely, the salesman did not seem aware of it.

"Well, it seemed to me to be an almost classical description of *petit mal*. When I returned home, I found your article and I sent it to my friend. He called me and said that the picture of the child with *petit mal* was exactly the look that the new employee had during the episodes described. My friend is going to use the article when he discusses with the salesman his observations in the hope that he will agree to examination by a neurologist. He has decided to keep him on as an employee."

Thank you for this opportunity to appear before you on behalf of the parents of the millions of children who live daily with this disorder.

[From the Commercial Appeal Mid-South Magazines, Dec. 2, 1973]

### EPILEPSY: WHY THE SECRECY, THE SHAME?

THE MOTHER OF AN EPILEPTIC CHILD PLEADS: 'WILL ANY FAMOUS PERSON WITH EPILEPSY PLEASE SPEAK UP? WE KNOW YOU'RE OUT THERE—HIDING LIKE ALL THE OTHERS'

By Marjorie Steitz

The night last year when our child Paul, age 11, had his first seizure, we were frightened and unsure as to whether something was really wrong or whether he was just having a nightmare. Like most parents, we knew very little about epilepsy and had only vaguely heard about "*petit mal*" and "*grand mal*" seizures. When he went back to sleep, we brushed it off as a nightmare.

The next morning, I joked with Paul—"That was some nightmare you had last night." He laughed too, adding, "You know, the funny thing is, it didn't seem as though I was having a nightmare. It was more like a movie scene." That made sense, and we smiled again—reassured by his good spirits—and off he went to school.

Then I started thinking. I tried to recall everything that happened the previous night when my husband and I were awakened by the commotion in Paul's bedroom. When we went in, he was lying on the floor by his bed, nose bleeding, drooling, trembling all over and breathing noisily. His arms and legs were thrashing. His eyelids were fluttering. I tried to wake him up. After a short interval, he did seem to be waking up, and we got him to his feet and into the bathroom, to wash his face.

He couldn't talk clearly and his eyes looked dull. We held him gently and soothed him, and soon the trembling and erratic breathing subsided and he was OK. He spoke clearly again. (We have since learned we did the right thing—a seizure must be allowed to run its course, with the parents simply protecting the child from self-injury. Some parents have attempted to "awaken" a child by hot baths or cold showers during seizures. This can be dangerous.)

A couple of nights later, Paul had another seizure, much like the first, and we realized something abnormal was happening. I took Paul to see our pediatrician, who asked us both a number of questions about the "nightmares." The doctor remarked there were sufficient symptoms of a seizure-pattern to warrant taking some lab tests and an EEG (electro-encephalograph) at a nearby hospital. He put Paul on phenobarbital.

Our doctor's attitude was calm and matter of fact, and since he was not alarmed, we weren't either. In ensuing visits, he unhesitatingly answered all of our questions, and explained to us a great deal about seizure-patterns. He never used the word epilepsy, because he said it is too emotional a word. "If you tell a parent his child has epilepsy, he hears nothing more you say. He is in a state of shock."

You need only consider that at least one in fifty Americans has epilepsy to wonder at the lack of public recognition of the problem. There are four million known epilepsy sufferers in the United States and many more unrecognized and untreated. By comparison, fewer than one-million Americans suffer from cancer, less than 500,000 from cerebral palsy and less than 75,000 from tuberculosis.

About 50 per cent of known epileptics have their attacks almost completely controlled by drugs and live normal lives. For the other half, treatment methods are

less effective. About 30 per cent have the frequency of seizures reduced markedly, while the remaining 20 per cent show almost no response to treatment. The reasons aren't altogether clear, although doctors are optimistic that medical research will soon achieve a breakthrough in relieving their anguish.

We know now that the prognosis for Paul is good, as it is for many youngsters who are put on medication promptly and gain control over their seizures promptly. The fewer the seizures the better the outlook. Paul's attitude is upbeat, partly because he can communicate with his doctor who answers questions honestly and patiently, and partly because friends and neighbors have taken an attitude of causal acceptance of Paul's disorder.

It isn't always so.

When we talk openly about Paul's case, we learn from many friends and neighbors that they too have relatives with seizure-patterns, and sometimes a person himself confesses he has epilepsy, but keeps quiet about it.

For instance, Mrs. Y., who lives two blocks away, told us her tale of tears, misunderstandings and fear, as she was shunted for three months from an emergency ward to a clinic to a neurologist's office and finally a third hospital with her 2-year-old daughter, Joyce. Her child was suffering repeated seizures daily. Mrs. Y. was exhausted, confused and frightened, because nobody bothered to sit down and answer her questions. Her anguish, we discovered, was all too frequent.

Physicians often fail to consider the emotional needs of parent and child. Even the most conscientious and sympathetic doctor hasn't the time to provide all the counseling services parent and child may require. He can't be expected to talk to the school principal or a prospective summer job employer, or spend half an hour with a parent explaining what an EEG is and what it tells. It is not necessarily the doctor's fault. In part, it's up to the patient's family to seek further information and guidance—which is widely available.

The Epilepsy Foundation of America (EFA), with chapters all over the country, is a wonderful source of information and help. If Mrs. Y. had gone to them at the beginning, she might not have found herself fighting off the tears, sitting by Joyce in her high chair, saying, "If I could just talk to someone who could answer my questions. If I could just talk to some other parents who have been through this. I look at other children in the grocery store, and they are normal, and Joyce isn't. Why?"

The question of "why" is often unanswerable. A probable cause can be given for about half the cases of epilepsy today, and research may shed light on more cases soon. There are many epilepsy research projects around the country, but the main center is the National Institute of Neurological Diseases and Stroke, a part of the National Institutes of Health in Bethesda, Md.

I remember well the day I walked across the Institute's rolling, well-tended lawns to talk to an expert. In an office walled from floor to ceiling with publications and charts, I found a totally un-austere neurologist, Dr. James Cereghino. He is one of a team of scientists studying "the epilepsies," as they call them, and he is as sensitive to the social problems of people with epilepsy as he is involved in the related medical research. He wants to tell you everything known, immediately, in words you can understand.

Some facts: Epilepsy is not a disease. It is a term (derived from the Greek, meaning "seizures") to describe both a set of symptoms and the underlying mechanism that causes them. Precisely, it is "recurring, uncontrolled electrical discharges of brain cells." The symptoms of epilepsy are called "seizures" because people used to think that a victim had been "seized" by an evil spirit. Incredibly, some people still do.

Seizures can vary from a twitch of an eyelid or a pain in the stomach to violent tremors all over the body. They can last a few seconds or a few minutes. They can be frequent or seldom. Sometimes, as with our son Paul, there is a warning or "aura." Traditionally, scientists divided epilepsies into little (petit mal), big (grand mal), and temporal lobe (psychomotor), because these afflictions were first described by their symptoms.

After the EEG was developed to measure electrical activities of the brain, it became possible to know where, when and how long electrical disturbances occur, what brain cells start the action, and how intense the electrical discharges are. Now there is an international classification of epilepsy type and seizure type.

Epilepsy is not contagious. It is not necessarily progressive. It has nothing to do with intelligence, emotional makeup, economic or ethnic background. About 75 per cent of all cases occur in the first 20 years. Heredity plays only a small role. Many forms of epilepsy are the result of brain damage at birth, or after birth

from organic injury, such as a blow from an accident. This type is not inherited, and cannot therefore be passed on to children. However, in "Idiopathic epilepsy" (which simply means the cause is not known), some tendency to inheritance does exist. (Doctors often are reluctant to use the term "Idiopathic," for some people associate it with "idiots," which seizure-prone children certainly are not.)

Very little was done scientifically to investigate epilepsy until the late 19th Century, when German scientists turned their attention to this classic superstition-enshrouded malady. The first big breakthrough in seizure control came with the discovery in 1912 that phenobarbital helped—nobody really knew why. The next milestones were the discovery of dilantin and the EEG, in the 1930s. Now there are 14 drugs on the United States market for epilepsy.

An important new tool in clinics is "GLC," or Gas-Liquid Chromatography, which measures levels of medication in the blood samples of epilepsy patients. This can tell a doctor promptly if the patient is taking his medicine or not and if it's effective. Research is inching ahead with new discoveries in surgery and telemetry as well as drug therapy.

History points out that St. Paul, Socrates, Caesar, Dante, Luther, and Napoleon all almost certainly had epilepsy. But name one famous person today who has epilepsy! There is a strange silence.

Sadly, prejudice and superstition are still so alive in the land that very few prominent people in any profession or business feel they can publicly admit to having it. Apparently, they feel their careers would be endangered. If one out of 50 people is seizure-prone, wouldn't there be some congressmen afflicted? One senator? Wouldn't his story of achievement be helpful to today's young victims and their parents? Although epilepsy research has many friends in Congress, who help get the funds to carry on the research, there are no prominent politicians who admit to a seizure-pattern.

No actress, tycoon, sport star either? If they only knew how much they would help others by speaking out—those few prominent people who do have epilepsy—perhaps they would risk exposure.

According to EFA studies, prejudice is diminishing slowly. The School Alert program is a promising step. If a child has a seizure in a classroom, and the teacher is frightened, his classmates most certainly will be, too. And he will suffer embarrassment at best, ostracism at worst.

The School Alert Kit explains to teachers, school nurses and students and parents what a seizure is and how to handle it in the classroom. Five thousand kits were sent across the nation by the foundation last year, and the program is going over well. As more teachers understand seizures, there will be fewer victims sent home by a frightened, unknowing teacher who can't cope.

A newer national program is Police Alert. It shows police how to distinguish someone stumbling with a seizure from someone drunk, and how to help him. Next on the drawing board is a Lifeguard Alert program, enabling seizure-prone children to swim safely.

But what we really need is a People Alert program. You can make the life of a child in your neighborhood much easier by simply offering him understanding and the respect you would offer anyone else.

If you are the parent of a child with seizure-pattern, please don't hide it. Talk about it; get information available to you. Some child's neurons may have misbehaved, but science can control most of them now and will some day discipline all of them. Superstition, not an erratic neuron, is the work of the devil.

Mr. KYROS. Thank you, Mrs. Steitz. It's a very moving statement.

Our next witness on the panel will be Mr. James A. Autry, the editor-in-chief of *Better Homes and Gardens*.

Welcome to the committee, Mr. Autry.

### STATEMENT OF JAMES A. AUTRY

Mr. AUTRY. Thank you very much.

As part of my statement I have submitted an article published in *Better Homes and Gardens* in June of this year concerning epilepsy and other brain disorders.

Information and public health education must be a No. 1 priority in the field of epilepsy. We have a number of informational programs underway. As you have heard all of them, though restricted by limited budgets, set the pattern for a continuing effort.

For instance, there is epilepsy month, designed to alert local communities to the needs of epilepsy. This is handled primarily by volunteers who in their local communities request free public service announcements on radio and television. But the free time we get does not begin to match that of other health organizations which have strong Government support, causes such as alcoholism, drug abuse, or venereal disease.

Another program is School Alert, which provides educational materials to teachers, school nurses, and students.

In 1973 demand for the materials doubled to much beyond the available number of study and work kits. School Alert has received commendations from the National Education Association and the American Association for Health, Physical Education, and Recreation, but a recent request for a small amount of funding from the Bureau of Education was rejected.

Available consumer literature is completely authoritative and is attractive, but limited financial resources place this material in a constant back-order situation.

By using a basic correspondence list an attempt has been made to survey both patients and parents of children with epilepsy. Results were encouraging, and we now have guidelines for informational activities, but to change attitudes as Mr. Gallup will explain, I am sure, a constant massive communications effort and a constant evaluation of progress are required.

In fact, Mr. Neal Gilliatt, vice chairman of the Interpublic Group of Companies, one of the largest marketing and advertising agencies in the world, has stated that at least \$4 million a year is required to sell one simple idea to the American public. He maintains that we must identify the problem, solve it from a communicator's viewpoint, then back it—to all segments of the public—with substantial media support and frequency.

What segments of the audience are we trying to reach? They are many.

One, the general public, with particular emphasis on the poor and less educated;

Two, pediatricians, internists, and general practitioners whose busy schedules prevent them from having the time to discuss the disorder in depth with patients;

Three, nurses and school nurses;

Four, educators;

Five, parents and patients themselves;

Six, vocational rehabilitation specialists, employers, unions, hospitals, religious and fraternal organizations;

Seven, insurance companies, Federal, State and local government agencies, and

Eight, legislators.

For each of these groups the epilepsy story must be presented differently to explain how it affects their daily lives and work.

The other members of this panel have told you from their personal experience and knowledge the specific informational needs which could be met by a national plan. But we must also include analysis, data gathering, planning, creative materials, extensive and frequent use of media, and a measurement of the efforts needed to attain the objectives.

I suppose every special cause that comes before you gentlemen considers itself unique. And I'm sure each has unique characteristics. But I really doubt that there is now another health problem whose victims are often less victimized by the affliction itself than by the ignorance, superstition, and fear and they must face in their everyday lives. I doubt that there is another disorder whose victims can be helped so dramatically in a medical sense yet then made to suffer the social pains of discrimination and embarrassment. I can't imagine a cured cancer patient who would not cry out with joy, "I beat cancer." But it's often tough to convince a controlled epileptic to admit, "I beat epilepsy."

This is why we here set such a high priority on information and education.

We must show people how to live with epilepsy. We must show the person who has epilepsy how to live with himself, fully and productively. We must show all those who deal with him or her that this is a full and productive person.

We have to make this a national problem for the Nation to solve and we need a national plan to do it. There is a ground swell in motion among the Congress, the people, the professionals, and this is the time for us to see it and direct it.

As the 4 million people with epilepsy and their families and friends begin to speak again to be their own best advocacy, begin to be their own best defenders, they will become a positive force for the solution of the Nation's health problems.

There is a motto on the masthead of the Scripps-Howard newspapers that we would offer as a guide to this day \* \* \*

"Give light and the people will find their own way." And we feel this bill can provide a great deal of light.

Thank you.

[Testimony resumes on p. 142.]

[Attachment to Mr. Autry's statement follows:]

[From the Better Homes and Gardens, June 1974]

#### WHAT YOU SHOULD KNOW ABOUT EPILEPSY, PARKINSON'S DISEASE, MULTIPLE SCLEROSIS, AND OTHER BRAIN DISORDERS

(By Gerald M. Knox)

The human brain and central nervous system are awesome instruments, far more advanced than the most sophisticated man-made computer. Many of their inner secrets defy even the most inquisitive investigators. But at last science is beginning to understand many of the brain's complexities. In laboratories around the world, researchers are assembling, fragment by tantalizing fragment, a fascinating mosaic of the subtle chemical, biological, and physical processes that govern every human thought, emotion, and action.

And as we have learned more about how these organs function, we are also discovering why they sometimes malfunction. One official of the National Institute of Neurological Diseases and Stroke (NINDS) says, "We have learned more about some neurological disorders in the past 25 years than we did in the previous 2,500." Since fuller knowledge is preliminary to better treatment

and control, this is indeed heartening news for many Americans and their families.

Disturbances of the brain and central nervous system have historically been among the most tragic, disabling, and intractable scourges of mankind. Not only do these disorders claim lives, but they sentence many to a lifetime of total or partial disability, and sap medical and financial resources far out of proportion to the numbers afflicted. *Amyotrophic lateral sclerosis (ALS)*, for instance, afflicts only about 9,000 Americans and claims 1,400 lives a year, yet the cost of caring for these victims is estimated at over \$37 million annually.

Most tragic of all, because neurological disorders sometimes produce bizarre physical behavior, popular opinion confuses them with mental illness—even though the victim's mental powers frequently are unimpaired. The epilepsy patient, for instance, has been shunned for centuries, even though many great men of history, including Julius Caesar, Alexander the Great, and Dostoevski, were thought to be subject to seizures.

The roll of neurological disorders includes one of the most publicized and dramatically controlled—*polio*; and one of the most commonplace—*headache*. The NINDS estimates there are between 200 and 300 other disabling conditions of the brain and central nervous system, including those resulting from disease, tumor, or injury. Some relatively rare conditions have been widely publicized, such as *ALS*, still known as "Lou Gehrig's disease" for the star baseball player struck down in his prime, and *Huntington's disease*, a hereditary incurable degeneration of the brain cells which killed folk singer Woody Guthrie.

But the most common neurological disorders fall into ten rough groupings. Research has not advanced uniformly against all of them; there remain many mysteries and murky areas. But in virtually all cases the outlook is more optimistic than in the past. Here is where we stand today:

Epilepsy represents one of neurology's recent success stories, from a scientific point of view, at least. The effects of the disorder have been known since Biblical times; ancients "possessed by devils" undoubtedly were victims of epileptic seizure. Science now knows that epilepsy is not a disease, but only a symptom. And, thanks to new drugs and more precise methods of detection and analysis, seizures can actually be eliminated in about 60 percent of victims—and controlled in 20 percent of others. Today, epilepsy patients can typically hold jobs, marry, and lead seizure-free lives.

About two million Americans have had at least one epileptic seizure; three million more may be "secret" epileptics, unaware of their condition or hiding it in fear of discrimination against them simply because they have the condition. About half the victims are under 20. The seizure occurs when abnormal electrical discharges in the brain trigger nerve cells, controlling certain body movements, causing erratic behavior. The electrical malfunctioning may be caused by brain injury, a disease such as meningitis, a brain tumor, or a congenital condition. In more than half the cases, no cause can be identified.

There are four chief types of seizures. *Grand mal* ("great sickness") is the most dramatic. The victim may cry out, become rigid and even temporarily cease breathing, then fall unconscious and thrash for perhaps minutes in violent jerks of the entire body. He may bite his tongue or lose control of his bladder before the attack subsides and he falls into a typical deep sleep. Although frightening to the onlooker, the attacks offer no physical danger to the victim unless he falls where his head might strike a hard object, but they are, of course, a tremendous embarrassment to him. *Grand mal* seizures often respond well to treatment.

*Petit mal* ("little sickness") mainly afflicts children. Its victims have "blank" or staring spells that last seconds and occur as often as several times a day. The child may even be unaware of them. *Petit mal* seizures usually disappear by age 18, or may continue as other types of seizures.

*Focal seizures* originate in one part of the brain. The spasm may start in a single finger or toe and then march up the body as more and more cells become affected until the whole body is involved.

*Psychomotor seizures* are a particular form of focal seizure which seems to begin in the temporal lobe over each ear, and appear to have emotional as well as physical reactions. The victim may be overwhelmed by a sudden vague fear.

He may push away people who try to help him, fumble with his clothes, and fling his head and arms around. Psychomotor seizures are the most difficult to treat.

Fortunately, epilepsy can quite often be diagnosed by an electroencephalogram, which measures brain waves by placing electrodes over many areas of the scalp. Even during a seizure-free period, the epileptic's EEG may show a distinct spiky pattern. Telemetry is also being used in difficult cases. This allows recording of brain waves for longer periods under more varied conditions than ever possible with the standard EEG recording.

Drugs have been used to combat epilepsy since the 1880's, but the most successful ones have come along in the last 30 years, and some in the last ten. Fourteen drugs now are used singly or in combination to reduce the intensity or frequency of seizures. And through a technique called gas-liquid chromatography, a doctor can now measure the precise amount of anticonvulsant drugs in a patient's blood, and prescribe the individual dosage which will help him most.

While not as much progress has been made in the social sphere against epilepsy, there have been gains. Pressure by the Epilepsy Foundation of America and others has resulted in the relaxation of many legal restrictions on epilepsy patients. For instance, most schools now accept them on medical certification that seizures can be controlled; the old laws prohibiting marriage between epilepsy patients have largely disappeared. The U.S. Civil Service Commission now forbids hiring discrimination against persons who have been seizure-free for two years, and many states now grant driver's licenses under the same condition. However, unofficial barriers remain. For instance, many epilepsy patients can obtain driver's licenses but cannot qualify for insurance—which effectively bars them from driving. Still, the fight for such simple human rights is making real headway.

Parkinson's disease is a second success story. This progressive paralytic disorder affects 1½ million Americans, mostly over 50 years of age, and its symptoms are unmistakable. The victim walks in a hunched shuffle, arms held rigidly at the sides, hands trembling, his face an expressionless mask. Often he will seem unable to start a movement and then be unable to stop it once begun. Although the disease is seldom fatal, the symptoms worsen until the patient is totally disabled.

Thanks to a drug called L-Dopa, three out of four Parkinson's victims now can be markedly helped. The drug builds on an earlier finding that Parkinson's disease is caused by a progressive failure of nerve tissue in the brain stem to produce a neurotransmitter. This chemical messenger which carries messages from one nerve cell to another is called dopamine. L-Dopa seems to stimulate the production of dopamine and raise its levels to near-normal.

About one in four Parkinson's victims cannot tolerate the heavy daily doses of L-Dopa because of serious side effects that sometimes produce new spasms and involuntary movements. Moreover, L-Dopa apparently has no lasting effect: once the treatment is stopped, the symptoms return. Thus the search for a better drug goes on. Dr. Melvin D. Yahr of the Parkinson's Disease Research Foundation and other researchers now are experimenting with L-Dopa in combination with other substances which might eliminate the side effects.

Other research is seeking to discover the cause of the disease. All that is known for sure is that one variety comes as the aftermath of encephalitis. Possible causes for the other varieties of Parkinson's include a slow-acting virus which lies dormant for years in the body, a dietary deficiency, a genetic weakness, and a buildup of metallic poisons in the system. The latter theory is given support by the discovery that manganese poisoning can cause symptoms like Parkinson's.

Multiple sclerosis seems to present a bleak picture, yet it is one of the neurological disorders investigators are optimistic about. "MS" afflicts between 100,000 and 250,000 Americans (with another 250,000 having closely related disorders). Three out of five of these victims are women and most, tragically, in the prime of their lives—between 20 and 40. It is a progressive disease of baffling origin which occurs more often in cool climates than in hot ones. There is no cure and very little effective treatment.

The disease results from the destruction of the fatty myelin tissue which insulates and protects the nerve fibers of the brain and spinal cord. The destruction occurs in irregular patches and in more than one location, giving rise to the term "multiple." Once the loss has occurred, the demyelinated nerves can no longer send the proper signal to the motor neurons. Early warning signs are

slurred speech and patches of tingling and numbness. Later the victim may stumble unsteadily, have double or blurred vision, or feel extreme weakness.

According to Dr. Robert Layzer of the University of California, the first MS attack usually strikes suddenly, and lasts several weeks. Then the condition may seem to disappear, not to recur for several months or years. Some people never have a second attack, but most are stricken repeatedly, with intermittent periods of apparent improvement. Many victims are never severely disabled, but in some the attacks usually become more severe and progressively disabling as more and more of the nerve cells are scarred by demyelination. Eventually the patient may be unable to stand, walk, control his bladder, or see properly. Still, most victims have a normal lifespan and some can even continue working. One study showed that 35 percent still held jobs 15 to 20 years after the first attack.

The on-again, off-again nature of MS makes it difficult both to diagnose and treat. Doctors never know whether improvement results from therapy or is simply a natural interlude of remission. And early symptoms are so vague that some cases go undetected for years. Even when a doctor suspects MS, he may hesitate to diagnose it until a second attack confirms his opinion. Six years usually elapse between the first symptoms and the final diagnosis. Once MS is identified, little can be done to help the victim. Neither drugs nor other therapies have been consistently successful. However, rehabilitation can help some patients maintain skills, since the nerves themselves are not destroyed.

The big hope in MS, however, lies in research. Investigators now feel that they may be closing in on the cause which has eluded them for so long. In 1972, Congress established a national advisory commission to review the status of MS research and help coordinate efforts. Four promising avenues are being pursued. One line of investigators seeks an environmental explanation, since MS occurs more frequently in the temperate zones of this country and throughout the world than in the tropical and subtropical ones. A second is a basic study of the body's myelin-building process, which may lead to understanding why the process sometimes goes wrong. A third seeks a slow-acting virus or perhaps a delayed reaction to a common virus. The fourth hypothesizes that MS is caused by a malfunction of the immunological system, which causes the body to attack its own myelin as if it were an invader.

The most intriguing explanation of all, according to UC's Dr. Layzer, is one that combines (3) and (4). The theory is that a virus may cause some trivial damage to the tissue, altering it into a foreign substance that sets off an auto-immune reaction. This explanation is partially borne out by the discovery that ACTH, a steroid hormone which is used to treat immunological disorders, appears to have some limited success against MS. The theory is being further studied by scientists who have reproduced a related disease of immunological origin in the laboratory animals.

Cerebral palsy, like epilepsy, is not a disease at all, but only a symptom—a group of conditions affecting muscular control that arise from damage to the developing brain, usually before birth. Because brain damage cannot be corrected, there is no cure. However, recent advances can help prevent further cases in the future, and aggressive rehabilitative therapy can help minimize its effects.

Most cerebral palsy is evident early in the infant's life. About half the 750,000 victims are *spastic*. Their tightly contracted muscles make them walk with a lurching gait, fling their arms and toss their heads, and speak in a guttural voice. Most of the other victims are *athetoid*, with constant, uncontrolled motion of the limbs. Less common is the *ataxic* form of cerebral palsy, marked by poor balance and frequent falls, and by tremor of the hands and feet. The type is determined by which portion of the brain has been damaged. Some victims are only mildly affected and live relatively normal lives; others are affected in only one limb, or on one side of the body. And some have a mixture of several types of cerebral palsy and have visual and hearing defects as well.

Cerebral palsy often seems to be related to conditions in early pregnancy—and even before—such as poor nutrition, poor health, anemia, toxemia, and exposure to toxoplasmosis, German measles, and other diseases. Diseases which strike in the last months of pregnancy, when the brain and spinal cord are maturing, can be especially dangerous. Other cases arise at birth, from complications of delivery or from injury or infection or oxygen deprivation. Premature babies and those of low birth weight appear particularly susceptible. Some rare forms

of CP, such as *Lesch-Nyhan Syndrome*, come from an inherited enzyme defect. A continuing eight-year study of 58,000 pregnancies and their offspring is expected to shed further light on the causes of cerebral palsy. One entire volume of the study will be devoted to children in the group who displayed the condition.

Although drug therapy has helped some cerebral palsy victims relax tensed muscles, its value has been limited. Yet a new drug, dantrolene sodium, which has helped some victims of cerebral palsy to lead near normal lives, was recently approved by the FDA. The drug relieves spasticity which stems from over-activity of the muscles. It acts on the muscle fiber itself and not on the central nervous system.

Surgery also can sometimes make walking easier for some spastics by severing nerves controlling contracted muscles and by lengthening heel cords to relax tense calf muscle. Now muscle transplants are being attempted. Dr. Irving S. Cooper of St. Barnabas Hospital, New York, recently reported that he had been able to halt the constant motion of athetoid CP in half of selected cases by freezing small parts of the brain. And cerebral palsy clinics—mustering physical, emotional, educational, and speech therapy under one roof—have helped many victims live more normal lives. With special training and appliances, even some of the most severely disabled children can learn to walk adequately and talk understandably by the age of six.

The headache is by far the most common neurological disorder—so common that no one can reliably estimate the number of its victims. For many people its occurrence is sporadic, to be briefly endured and forgotten. But for others, it is a disabling ailment, so severe and frequent as to prevent the victim from working or leading a normal life. Yet, progress is being made toward understanding what actually causes headaches and how to treat and prevent them.

Apart from headaches that are caused by injury, illness, or tumor, most fall into two types.

Muscle contraction headaches strike because the person involuntarily holds his neck and scalp muscles in a tense position for a long period. Muscle contraction headaches can temporarily be overcome by heat, massage, or a muscle relaxant.

Migraine headaches, however, occur periodically, spontaneously, and without apparent cause. About two-thirds of the sufferers are women, and about half come from families that have a history of migraine headaches.

"Migraine" is derived from the Greek word "hemicrania," meaning "half the head," and the term precisely describes classical migraine. The attack generally occurs on only one side of the head, usually the same one in each attack, and is often marked by a visibly throbbing artery in the temple and by nausea and vomiting. Often the victim is warned of the headache by an "aura," in which he sees sparkling dots and spots, zigzag lines, or heatwaves, or is even temporarily blinded in one eye.

The great headache authority, Dr. Harold Wolff of Cornell Medical School, taught that migraine was triggered by emotional stress and could only be successfully treated by psychotherapy. A growing number of researchers now consider both the definition and the explanation too narrow. Many headaches do not meet all the criteria of classical migraine, yet are not muscle-contraction headaches. A woman's headache during menstruation is one example. These researchers believe that headaches result from some malfunction in the centers of the nervous system which control blood vessel dilation and contraction, and that this malfunction is related to the amounts of certain chemicals circulating in the blood.

Supporting this theory is an increasing body of evidence that certain foods—such as cheese, chocolate, and some hot dogs—which have high percentage of the suspect chemicals can in some individuals produce a migraine-like headache. If this discovery can be confirmed, it may lead to better means of headache control—and prevention.

For severe migraine sufferers, a new family of medicines has been introduced within the past decade. This medication, taken daily, can either stave off or reduce the headache's effects in 60 to 75 percent of severe cases, according to Dr. Neil Raskin of the University of California. For some people, however, the medication causes serious side effects which limit its usefulness.

There is still a note of cheer, however, for all migraine sufferers. Migraine headaches, for reasons unknown, generally decrease in frequency and severity after the age of 40.

Narcolepsy is a relatively rare condition whose victims find themselves overwhelmed by an uncontrollable desire to sleep. They may suddenly drop to the

ground while walking or doze off at work, at school, or even while eating. The naps may last from a few minutes to hours.

The disorder is neither dangerous nor life-threatening, although certainly inconvenient for its victims. According to Dr. William Dement of Stanford University, narcoleptic sleep seems related to the rapid-eye-movement phase of normal sleep which accompanies dreams, and may result from a disorder of the nerve centers controlling that process. Investigators have been handicapped in their study of narcolepsy by the fact that no parallel condition exists in animals which can be studied in the laboratory. The disorder often can be alleviated by drugs.

Brain tumors strike over 10,000 Americans a year and kill 8,000, many of them children under ten. Although modern treatment can keep victims of certain forms of brain tumor alive far longer than in the past, the overall cure rate has improved only slightly over the past few decades.

Brain tumors are baffling because their symptoms mimic many other disorders. Depending on the growth's location, the victim may have failing eyesight, hearing loss, dizzy spells, unusual sleepiness, sudden bouts of irritability, or even loss of emotion or intellect. Moreover, many tumors which would be considered benign elsewhere in the body are life-threatening in the brain, because in growing within the confined space of the skull they crowd healthy cells and interfere with or destroy their function. However, these tumors are usually encapsulated and if discovered early may be completely removed surgically. Malignant tumors, on the other hand, sometimes have roots like a plant and removing them completely is difficult without destroying large portions of essential brain tissue in the process. Moreover, some brain tumors are secondary tumors, "seeded" by cancerous cells from a primary tumor elsewhere. Breast and lung cancers and the so-called "black cancers" of the skin seem particularly prone to spread to the brain. Sometimes it is possible to cure the primary tumor but not its satellite growth in the brain.

Surgery and radiotherapy remain the chief weapons against brain tumor, but the great hope lies in drugs. Used alone or in combination with radiotherapy, certain drugs have shown promise in reaching malignant cancers which cannot be attacked by other means. The chief obstacle to greater use of drugs is the "blood brain barrier," a process by which the body filters presumably harmful substances out of the blood before they can reach delicate parts of the brain. The National Cancer Institute is vigorously investigating ways to penetrate this barrier.

Meanwhile, emphasis is on early detection and rehabilitation. People are urged to undergo a complete physical examination when they notice any sudden and unusual change in habits, from personality traits to visual ability. A sophisticated technique called the brain scan, which records concentrations of injected radioactive material in cancer cells, can locate tumors in the very early and most curable stages. For those people who have been treated for brain tumors and left with some functions impaired, rehabilitation can now lead to more normal living.

Brain injuries—from accidents, falls, and blows to the head—claim an estimated 50,000 lives a year and hurt perhaps three million other people. Of all the many brain and central nervous system disorders, brain injuries are the ones most likely to strike the average American family.

Brain damage may occur as a result of the brain's impacting against the interior of the bony skull, causing bruises or lacerations which can have permanent effects. Or there may be internal bleeding or bleeding over the entire surface. Sometimes the injured brain swells or fluid collects, putting pressure on the cells. There may also be damage from an object's penetrating the skull and brain, or from depressed skull fracture which bruises the brain beneath it.

According to neurologists, you should be concerned about any head injury which involves increasing loss of consciousness or causes paralysis or other disturbance of brain function. And Dr. Gary Goldstein of the UC's pediatric neurology branch suggests that parents watch for the following signs after a head injury to children:

- Unconsciousness for more than a few seconds
- Persistent vomiting
- Dilation of one eye pupil
- Limb weakness
- Convulsions

A second bout of nausea, more severe than which followed the accident.

Although parents are frequently cautioned to wake up an injured child every hour or two, to check his condition. Dr. Goldstein demurs. He suggests that if parents are that concerned, they should immediately seek medical attention.

Mr. KYROS. Thank you, Mr. Autry.

Now, we have finally on the panel the statement of Dr. George Gallup, Jr. president of the American Institute of Public Opinion.

Welcome to the committee, Mr. Gallup.

### STATEMENT OF GEORGE GALLUP, JR.

Mr. GALLUP. Thank you, Mr. Chairman. I am honored to be a witness at these hearings.

I have the results of the nationwide survey on epilepsy that we recently conducted for the National Institutes of Health.

You will find the detailed findings attached to my statement [see p. 145].

The results show a dramatic rise in enlightenment over the last quarter century of attitudes toward epilepsy and accordingly a remarkable decline in prejudice to it.

Now, let me read you just a few of the key findings; 25 years ago, in 1949, 45 percent of American adults believed that epileptics should not be discriminated against in terms of employment. Today 81 percent hold this opinion.

In 1949, 24 percent said they would object to having their children go to school or play with epileptic children. Today, only 5 percent would object.

In 1949, 13 percent of persons interviewed thought epilepsy was a form of insanity. Today, the comparable proportion is only 2 percent.

The current survey also shows that a very high proportion of Americans, 94 percent, have heard or read about epilepsy. Six in 10 or 62 percent say they have known someone who has epilepsy, while six in 10 or 60 percent also say they have seen a person having a seizure.

Now, what are some of the reasons given for these rather dramatic changes?

Well, Dr. Caveness who is associated with the National Institutes of Health, offers these reasons, among others.

Factors that have contributed to the more enlightened opinion of the public include an overall improvement in public attitudes toward dread diseases such as tuberculosis, syphilis, and cancer; improved medical control of seizures; educational efforts by professional and lay societies regarding epilepsy; employment by a number of major industries of individuals with a history of attacks; and eased legal restrictions for epileptics concerning immigration, marriage, and the operation of motor vehicles.

Well, while these findings are indeed dramatic in terms of increased public enlightenment, there remains considerable room for improvement.

Eight percent of Americans, or a projected 11 million, believes epileptics should not be employed in jobs like other people, while still others express uncertainty.

Five percent, or a projected 7 million Americans, object to having their children associate with persons who have seizures while still others express uncertainty on this matter.

Two percent, or a projected 3 million, believe that epilepsy is a form of insanity, while still others express uncertainty.

Forty-one percent of Americans, or a projected 57 million, are unable to give an opinion as to the cause of epilepsy. In addition, 6 percent, or a projected 8 million Americans, say they have not heard or read about epilepsy.

While there have been very dramatic gains in public enlightenment, there is clearly a long way to go as these figures would indicate, and it is very important to note that significant percentage of the persons are undecided or uncertain.

Certainly there are some who are giving us the responses they consider to be the acceptable answer to give.

While on the surface there are significant gains in enlightenment, there is of course a big gap between what people say they will do and what they actually will do.

There is clearly much need for further research, not only to set bench marks to determine if progress is being made in public enlightenment, but to dig into reasons why employers reject epileptics, why parents do not let children play with epileptics, there is apparently a stigma against epilepsy for operating in our society.

Well, since 1949, I should point out, the Gallup Poll has donated some \$50,000 worth of research in conducting six nationwide surveys on a completely gratis basis, and we stand ready to donate further research in ways to enlighten the public, as well as to monitor progress in this regard.

The need for a massive continuing education program is obvious, and the benefit of such a program is equally obvious from these results.

Therefore, I would respectfully request you gentlemen to make a continuing study of the epilepsy universe as part of the national plan. We need hard facts, knowledge, measurement of attitudes, a means of gauging efforts against objectives.

If we are to make progress, we must continually measure that progress.

Thank you for the opportunity to present these survey findings.

[Testimony resumes on p. 159.]

[Mr. Gallup's prepared statement and attachment follow:]

STATEMENT OF GEORGE GALLUP, JR., PRESIDENT, AMERICAN  
INSTITUTE OF PUBLIC OPINION

Public enlightenment regarding health problems has grown at a rapid pace in recent years. For example, attitudes toward epilepsy—a condition now afflicting an estimated four million persons—have undergone profound change over the last quarter-century.

Twenty-five years ago, in 1949, 45 percent of American adults believed that epileptics should not be discriminated against in terms of employment. Today 81 percent hold this opinion.

In 1949, 24 percent said they would object to having their children go to school or play with epileptic children. Today, only 5 percent would object.

In 1949, 13 percent of persons interviewed thought epilepsy was a form of insanity. Today, the comparable proportion is only 2 percent.

The current survey also shows that a very high proportion of Americans, 94 percent, have heard or read about epilepsy. Six in 10 (62 percent) say they have known someone who has epilepsy, while six in 10 (60 percent) also say they have seen a person having a seizure.

Beginning in 1949, and at regular five-year intervals since that time, the Gal-

lup Poli as a public service has conducted a national in-depth survey of public attitudes toward epilepsy for the National Institutes of Health in Bethesda, Maryland. The survey, conducted in close association with Dr. William F. Caviness, was reported in detail at the American Neurological Association meeting in Boston, June 10-12.

Factors that have contributed to the more enlightened opinion of the public include an overall improvement in public attitudes toward dread diseases such as tuberculosis, syphilis, and cancer; improved medical control of seizures; educational efforts by professional and lay societies regarding epilepsy; employment by a number of major industries of individuals with a history of attacks; and eased legal restrictions for epileptics concerning immigration, marriage, and the operation of motor vehicles.

While dramatic gains have been recorded in public enlightenment regarding epilepsy, there remains considerable room for improvement:

Eight percent of Americans, or a projected 11 million, believe epileptics should not be employed in jobs like other people, while still others express uncertainty.

Five percent, or a projected 7 million, object to having their children associate with persons who have seizures while still others express uncertainty.

Two percent, or a projected 3 million, believe that epilepsy is a form of insanity, while still others express uncertainty.

Forty-one percent of Americans, or a projected 57 million, are unable to give an opinion as to the cause of epilepsy. In addition, six percent, or a projected 8 million Americans, say they have not heard or read about epilepsy.

It should be emphasized that in addition to those who give a definite response, still others (as pointed out) express uncertainty or have no opinion.

Clearly, there is a reason to develop further programs to increase public enlightenment and to improve the lot of epileptics in our nation.

The survey results are based on in-person interviews with 1,504 adults, 18 and older, in more than 300 scientifically selected localities across the nation, conducted in January.

The design of the sample is that of a replicated probability sample down to the block level in the case of urban areas and to segments of townships in the case of rural areas.

After stratifying the nation geographically and by size of community in order to insure conformity of the sample with the latest available estimates by the Census Bureau of the distribution of the adult population, about 320 different sampling locations or areas were selected on a strictly random basis. The interviewers had no choice whatsoever concerning the part of the city or county in which they conducted their interviews.

Approximately 5 interviews were conducted in each such randomly selected sampling point. Interviewers were given maps of the area to which they were assigned, with a starting point indicated, and required to follow specific directions. At each occupied dwelling unit, interviewers were instructed to select respondents by following a prescribed systematic method and by a Male-Female assignment. This procedure was followed until the assigned number of interviews was completed.

Since this sampling procedure is designed to produce a sample which approximates the adult civilian population (18 and older) living in private households in the U.S. (that is, excluding those in prisons and hospitals, hotels, religious and educational institutions, and on military reservations), the survey results can be applied to this population for the purpose of projecting percentages into numbers of people. The manner in which the sample is drawn also produces a sample which approximates the population of private households in the United States. Therefore, survey results can also be projected in terms of numbers of households when appropriate.

The need for a massive, continuing educational program is obvious. And the benefit of such a program is equally obvious from these results. Therefore, I would respectfully request you gentlemen to make a continuing study of the epilepsy universe as part of the national plan. We need hard facts, knowledge, a measurement of attitudes, a means of gauging efforts against objectives. If we are to make progress, we must continually measure that progress.

**A SURVEY OF PUBLIC ATTITUDES TOWARD EPILEPSY IN 1974 WITH AN  
INDICATION OF TRENDS OVER THE PAST TWENTY-FIVE YEARS**

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**To Be Published In EPILEPSIA**

## MATERIALS AND METHODS

In 1949, a series of questions were framed by William G. Lennox, H. Houston Merritt, and William F. Caveness to gain some concept of the attitudes throughout the United States toward epilepsy as it related to the intellectual, social and economic spheres of our society. These queries were asked by Gallup in a survey conducted by the American Institute of Public Opinion; 1,504 responses were elicited from the adult (18 and older), non-institutional, civilian population by the institute's personal interviewers. The survey was designed so that every major group in the population was represented in proper proportion.

The design of the sample is that of a replicated, probability sample down to the block level in the case of urban areas, and to segments of townships in the case of rural areas. Approximately 300 sampling points, i.e., clusters of blocks or rural segments were selected for the latest survey.

The reader should bear in mind that the survey findings reported here are subject to sampling error. The following table shows the size of the error for samples as small as 200 and ranging up to 1500. The figure represents the limits within which a percentage will range 95 times in 100. For example, if the result is based on 200 cases and the percentage is near 40, then the odds are 95 in 100 that this figure will fluctuate no more than 9 percentage points in either direction—that is, from 49 to 31. If the result is based on the questioning of 1500 persons then the odds are 95 in 100 that the fluctuation will be within 3 percentage points in either direction or 42 to 38.

	In Percentage Points (at 95 in 100 confidence level)				
	Sample Size				
	<u>1500</u>	<u>1000</u>	<u>600</u>	<u>400</u>	<u>200</u>
Percentages near 10	2	2	4	4	5
Percentages near 20	2	3	4	5	7
Percentages near 30	3	4	5	6	8
Percentages near 40	3	4	5	6	9
Percentages near 50	3	4	5	6	9
Percentages near 60	3	4	5	6	9
Percentages near 70	3	4	5	6	8
Percentages near 80	2	3	4	5	7
Percentages near 90	2	2	4	4	5

To measure the trend in public attitudes toward epilepsy surveys were also conducted in 1949 (Caveness), 1954 (Caveness), 1959 (Caveness), 1964 (Caveness et al.), 1969 (Caveness et al.).

## RESULTS FROM THE 1974 SURVEY

The questions asked with the responses recorded in the most recent poll are listed in tables 1 - 7.

TABLE 1

ANSWERS UPON THE QUESTION: "HAVE YOU EVER HEARD OR READ ABOUT THE DISEASE CALLED 'EPILEPSY' OR CONVULSIVE SEIZURES (FITS)?"

<u>Results:</u>	<u>Number of Interviews</u>	<u>Answers (total 100%)</u>	
		<u>Yes (%)</u>	<u>No (%)</u>
NATIONAL	1504	94	6
EDUCATION			
College	463	97	3
High School	803	98	4
Grade School	233	85	15
(undesignated	5)		
SEX			
Men	752	93	7
Women	752	95	5
AGE			
18 - 29 years	370	93	7
30 - 49 years	553	96	4
50 years & older	573	92	8
(undesignated	8)		
OCCUPATION			
Professional & Business	382	98	2
Clerical and Sales	178	98	2
Farmers	64	91	9
Manual Workers	560	94	6
Non-Labor Force	265	87	13
(undesignated	47)		
CITY SIZE			
500,000 and over	415	95	5
50,000 - 499,999	408	96	4
2,500 - 49,999	267	91	9
Under 2,500	424	92	8
REGION			
East	399	95	5
Midwest	406	98	4
South	451	92	8
West	248	90	10

TABLE 2

ANSWERS UPON THE QUESTION: "DID YOU EVER KNOW ANYONE WHO HAD EPILEPSY?"

<u>Results:</u>	<u>Answers (total 100%)</u>		
	<u>Yes (%)</u>	<u>No (%)</u>	<u>Not familiar with epilepsy (%)</u>
NATIONAL	62	32	6
EDUCATION			
College	72	25	3
High School	63	33	4
Grade School	47	38	15
SEX			
Men	62	31	7
Women	62	33	5
AGE			
18 - 29 years	58	35	7
30 - 49 years	66	30	4
50 years & older	61	31	8
OCCUPATION			
Professional and Business	70	28	2
Clerical and Sales	65	33	2
Farmers	60	31	9
Manual Workers	61	33	6
Non-Labor Force	54	33	13
CITY SIZE			
500,000 and over	61	34	5
50,000 - 499,999	64	32	4
2,500 - 49,999	55	36	9
Under 2,500	64	28	8
REGION			
East	63	32	5
Midwest	67	29	4
South	55	37	8
West	63	27	10

TABLE 3

ANSWERS UPON THE QUESTION: "HAVE YOU EVER SEEN ANYONE WHO WAS HAVING A SEIZURE?"

<u>Results:</u>	<u>Answers (total 100%)</u>		
	<u>Yes (%)</u>	<u>No (%)</u>	<u>Not familiar with epilepsy (%)</u>
NATIONAL	61	33	6
EDUCATION			
College	64	33	3
High School	63	33	4
Grade School	50	35	15
SEX			
Men	62	31	7
Women	59	36	5
AGE			
18 - 29 years	54	39	7
30 - 49 years	67	29	4
50 years & older	61	31	8
OCCUPATION			
Professional and Business	68	30	2
Clerical and Sales	57	41	2
Farmers	48	43	9
Manual Workers	61	33	6
Non-Labor Force	53	34	13
CITY SIZE			
500,000 and over	65	30	5
50,000 - 499,999	64	32	4
2,500 - 49,999	57	34	9
Under 2,500	54	38	8
REGION			
East	64	31	5
Midwest	62	34	4
South	57	36	8
West	57	33	10

TABLE 4

ANSWERS UPON THE QUESTION: "WOULD YOU OBJECT TO HAVING ANY OF YOUR CHILDREN IN SCHOOL OR AT PLAY ASSOCIATE WITH PERSONS WHO SOMETIMES HAD SEIZURES (FITS)?"

<u>Results:</u>	<u>Answers (total 100%)</u>			
	<u>Yes (%)</u>	<u>No (%)</u>	<u>No opinion (%)</u>	<u>Not familiar with epilepsy (%)</u>
NATIONAL	5	84	5	6
EDUCATION				
College	5	90	2	3
High School	5	87	4	4
Grade School	7	89	9	15
SEX				
Men	5	82	8	7
Women	5	86	4	5
AGE				
18 - 29 years	5	85	3	7
30 - 49 years	4	90	2	4
50 years & older	6	78	8	8
OCCUPATION				
Professional and Business	4	92	2	2
Clerical and Sales	2	93	3	2
Farmers	8	76	8	9
Manual Workers	8	84	4	8
Non-Labor Force	6	71	10	13
CITY SIZE				
500,000 and over	5	85	5	5
50,000 - 499,999	6	87	3	4
2,500 - 49,999	4	80	7	9
Under 2,500	5	82	5	8
REGION				
East	5	88	4	5
Midwest	5	86	5	4
South	7	79	8	8
West	4	82	4	10

TABLE 5

ANSWERS UPON THE QUESTION: "DO YOU THINK EPILEPTICS SHOULD OR SHOULD NOT BE EMPLOYED IN JOBS LIKE OTHER PEOPLE?"

Results:	Answers (total 100%)			
	Should (%)	Should Not (%)	No opinion (%)	Not familiar with epilepsy (%)
NATIONAL	81	8	5	6
EDUCATION				
College	87	8	4	3
High School	84	7	5	4
Grade School	65	13	7	15
SEX				
Men	77	11	5	7
Women	84	5	5	5
AGE				
18 - 29 years	83	8	4	7
30 - 49 years	85	5	5	4
50 years & older	74	12	6	8
OCCUPATION				
Professional and Business	92	3	3	2
Clerical and Sales	85	7	6	2
Farmers	65	13	13	9
Manual Workers	81	8	5	6
Non-Labor Force	66	15	8	13
CITY SIZE				
500,000 and over	85	5	5	5
50,000 - 499,999	84	8	4	4
2,500 - 49,999	77	10	4	9
Under 2,500	74	10	8	8
REGION				
East	83	6	8	5
Midwest	84	8	4	4
South	74	12	6	8
West	79	7	4	10

Cross tabulation. Of those who said epileptics should be employed, 4% objected to their children playing with epileptics, 92% did not object, and 4% gave no opinion. Of those who said epileptics should not be employed, 20% objected to their children playing with epileptics, 73% did not object, and 7% gave no opinion.

TABLE 8

ANSWERS UPON THE QUESTION: "DO YOU THINK EPILEPSY IS A FORM OF INSANITY, OR NOT?"

Results:	Answers (total 100%)			
	Yes (%)	No (%)	Don't Know (%)	Not familiar with epilepsy (%)
NATIONAL	2	86	6	8
EDUCATION				
College	1	93	3	3
High School	1	91	4	4
Grade School	4	86	15	15
SEX				
Men	2	84	7	7
Women	1	89	5	5
AGE				
18 - 29 years	1	88	4	7
30 - 49 years	1	92	3	4
50 years & older	3	80	9	8
OCCUPATION				
Professional and Business	1	93	4	2
Clerical and Sales	—	95	3	2
Farmers	7	77	7	9
Manual Workers	2	87	5	8
Non-Labor Force	3	74	10	13
CITY SIZE				
500,000 and over	1	90	4	5
50,000 - 499,999	1	91	4	4
2,500 - 49,999	2	82	7	9
Under 2,500	2	82	8	8
REGION				
East	1	89	5	5
Midwest	1	91	4	4
South	3	80	9	8
West	1	85	4	10

Cross tabulation. Of those who said epileptics should be given employment, 1% thought epilepsy a form of insanity, 95% did not, and 4% gave no opinion. Of those who said epileptics should not be given employment, 11% thought epilepsy a form of insanity, 76% did not and 13% gave no opinion. Of those who would not object to their children playing with an epileptic, 1% regarded epilepsy as a form of insanity, 95% did not, and 4% gave no opinion. Of those who would object to their children playing with an epileptic, 12% regarded epilepsy as a form of insanity, 73% did not, and 15% gave no opinion.

TABLE 7

ANSWERS UPON THE QUESTION: "WHAT DO YOU THINK IS THE CAUSE OF EPILEPSY?"

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<u>Results:</u>	(1413 cases ) <u>(%)</u>
Don't know	41
Brain disease, disorder, injury	10
Nervous system disease, disorder	16
Heredity, inherited disease	10
Birth defect	5
Other diseases, disorders	6
Mental or emotional stress, disorder	3
Blood, blood disorder	2
Damage, injury to nervous system, injury (non-specific)	1
Miscellaneous	4
	<hr/>
	98*
Not familiar with epilepsy	6
	<hr/>
	104*

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\* Multiple answers.

## TREND OVER THE PAST TWENTY-FIVE YEARS

The changes in attitude as reflected in polls conducted in 1949, 1954, 1959, 1964, 1969, and 1974 are indicated in the following tables (Tables 8-12), utilizing only the percentages of the national figures.

The figures in Table 8 indicate the consistently high proportion of the population that has been familiar with this disorder (changes of a point or two could be due to sampling error). More than nine in 10 (94 per cent) persons know about epilepsy. This represents more than 130 million adults (18 and older) based on the latest available census data for the adult, non-institutional, civilian population of the United States. Such knowledge was found in 98 per cent of the professional group, but somewhat less (84 per cent) of those whose education was limited to grade school.

From Table 9 it is evident that there is now far less objection by parents to their children playing or associating with epileptics. From 1949 this figure has declined by 27 percentage points. There remain 5 per cent (seven million people) who still object.

Public opinion regarding the relationship of epilepsy to insanity (Table 10) has shown considerable modification since 1949. Today 86 per cent disavow such relationship, and only 2 per cent, an estimated three million, actually believe epilepsy to be a form of insanity.

Opinions as to the cause of epilepsy (Table 11) have changed in the last 25 years primarily in the category of "don't know". There remain 4 per cent, approximately six million, in the "miscellaneous" category which includes bizarre causes such as demonic possession, exotic foods or beverages, and the like.

Table 12 deals with the important question whether epileptics should or should not be employed. Those who answered "yes" have increased by 36 percentage points over the 25 year period, but in 1974, there remained an estimated eleven million people who opposed the epileptic working.

Table 13 shows that favorable views have increased in all four major regions of the nation.

TABLE 8

ANSWERS UPON THE QUESTION: "HAVE YOU EVER HEARD OR READ ABOUT THE DISEASE CALLED EPILEPSY, OR CONVULSIVE SEIZURES (FITS)?"

---

<u>Year:</u>	<u>Answers (total 100%)</u>	
	<u>Yes (%)</u>	<u>No (%)</u>
1949	92	8
1954	90	10
1959	93	7
1964	95	5
1969	94	6
1974	94	6

TABLE 9

ANSWERS UPON THE QUESTION: "WOULD YOU OBJECT TO HAVING ANY OF YOUR CHILDREN IN SCHOOL OR AT PLAY ASSOCIATE WITH PERSONS WHO SOMETIMES HAD SEIZURES (FITS)?"

---

<u>Year:</u>	<u>Yes (%)</u>	<u>No (%)</u>	<u>Don't know or not familiar with epilepsy (%)</u>
1949	24	57	19
1954	17	68	15
1959	18	67	15
1964	13	77	10
1969	9	81	10
1974	5	84	11

TABLE 10

ANSWERS UPON THE QUESTION: "DO YOU THINK EPILEPSY IS A FORM OF INSANITY OR NOT?"

---

<u>Year:</u>	<u>Yes (%)</u>	<u>No (%)</u>	<u>Don't know or not familiar with epilepsy (%)</u>
1949	13	59	28
1954	7	68	25
1959	4	74	22
1964	4	79	17
1969	4	81	15
1974	2	86	12

TABLE 11

ANSWERS UPON THE QUESTION: "WHAT DO YOU THINK IS THE CAUSE OF EPILEPSY?"

---

<u>Results:</u>	<u>1949 (%)</u>	<u>1959 (%)</u>	<u>1969 (%)</u>	<u>1974 (%)</u>
Don't know	57	58	40	41
Brain, nervous system	22	27	30	26
Heredity, birth defect	12	13	19	15
Other diseases, injury	—	—	7	7
Mental or emotional	1	—	4	3
Blood disorder	2	1	3	2
Miscellaneous	7	4	2	4

TABLE 12

ANSWERS UPON THE QUESTION: "DO YOU THINK EPILEPTICS SHOULD BE EMPLOYED IN JOBS LIKE OTHER PEOPLE?"

---

<u>Year:</u>	<u>Yes (%)</u>	<u>No (%)</u>	<u>Don't know or not familiar with epilepsy (%)</u>
1949	45	35	20
1954	60	22	18
1959	75	11	14
1964	82	9	9
1969	78	12	12
1974	81	8	11

TABLE 13

## ANSWERS UPON THE VARIOUS QUESTIONS IN DIFFERENT REGIONS

Questions:	Year	East		Midwest		South		West	
		Yes (%)	No (%)	Yes (%)	No (%)	Yes (%)	No (%)	Yes (%)	No (%)
Familiar with epilepsy	1949	92	8	92	8	92	8	92	8
	1954	92	8	90	10	87	13	55	5
	1959	94	6	92	8	88	12	57	3
	1964	95	5	94	6	95	5	87	3
	1969	93	7	95	5	91	9	83	2
	1974	95	5	98	4	92	8	90	10
Object to children associating with epileptics*	1949	23	59	24	58	29	49	23	60
	1954	14	71	18	67	15	68	25	87
	1959	18	71	18	67	15	63	15	67
	1964	14	76	9	84	17	71	14	73
	1969	8	79	9	81	11	77	6	89
	1974	5	86	5	86	7	79	4	82
Epilepsy a form of insanity	1949	12	60	13	61	20	48	10	84
	1954	7	63	5	74	8	61	7	73
	1959	3	82	5	74	7	54	4	81
	1964	2	81	4	83	6	68	2	85
	1969	4	79	4	85	6	74	4	83
	1974	1	89	1	91	3	80	1	85
Should epileptics be employed	1949	51	33	45	34	33	40	44	36
	1954	66	19	59	22	53	25	53	24
	1959	83	7	71	13	58	17	84	9
	1964	85	7	85	6	72	17	89	4
	1969	75	10	78	12	68	19	89	5
	1974	83	6	84	8	74	12	79	7

\* "No opinion" and "not familiar" are omitted from the last 3 questions.

## SUMMARY

At five-year intervals during the past 25 years, the American Institute of Public Opinion has obtained answers to questions about epilepsy from representative samples of the U.S. adult population. During this period knowledge of epilepsy was found in 90-95 per cent of the people interviewed. When those familiar with epilepsy were asked if they would object to their children playing with epileptics, the upward trend in those without objections, from 1949 to 1974 was: 57%-68%-67%-77%-81%-84%. When asked if they thought epilepsy was a form of insanity, the trend in those who did not was: 59%-68%-74%-79%-81%-86%. When asked if epileptics should be employed, the affirmative answer steadily increased, as follows: 45%-60%-75%-82%-76%-81%. The adverse responses were proportionately reduced.

In each of the six surveys, the most favorable opinion was among the better educated, better employed, younger and urban members of the population. A change has been recorded in all four major regions of the nation, with the South now holding views not far out of line with the views of persons in the three other major regions of the nation.

Factors that have contributed to the more enlightened opinion include: an overall improvement in public attitudes toward dread diseases such as tuberculosis, syphilis, and cancer; improved medical control of seizures, educational efforts by professional and lay societies regarding epilepsy; employment by a number of major industries of individuals with a history of attacks and more reasonable legal regulations concerning immigration, marriage, and the operation of motor vehicles.

Mr. KYROS. Thank you very much, Dr. Gallup.

I will just ask a few questions of the panel.

Dr. SIMONDS, in the area of information and education, what would you like to have the Commission do, specifically?

Dr. SIMONDS. I have thought about this question during the hearings today and jotted down a few notes to myself.

I think the first thing that I would like to see would be an extension of the point that Dr. Gallup was making, not only a survey of attitudes and knowledge, but a study of the relationship between those surveys and the attitudes and what people actually do.

I think the testimony today has indicated a very wide discrepancy between what the attitudes that we are measuring and what people are actually doing in real life situations.

I think the second thing evolving out of those studies would come the development of a comprehensive public health education program, linking the mass media, particularly at the national level, which I think is very effective, and local health education programming efforts.

I think separately they are not adequate. I think joining together the mass media and the local education programs for the volunteers would be particularly effective.

I would say that a priority system for public health education would have to evolve, and each of us would have our priorities.

I happen to place a very high priority on prevention, and I think a vast educational program is indicated there. And I think a very high priority needs to be placed on preventing recurrence of seizures in very young children. The evidence appears convincing to me that educational attainment and perhaps IQ itself may be affected. Children may not develop their full potential if seizures are not prevented when they are very young, so I would give a very high priority to that.

But I think there are probably five or six very high priorities that would evolve out of a study like this that would deal with prevention, case finding and management, community care and community understanding regarding employment.

A major element which I don't think has been adequately represented is I think the educational program should include emphasis on the patients themselves.

My own research with patients with epilepsy indicates that a fairly large number are not taking their medications as prescribed, and part of the problem I think with epilepsy in the community is the patients run into problems as a result. As was presented earlier, there are many reasons for this, including some economic and some social, but the consequences are that many patients are not taking the medications that are available for them. I think a major educational effort is indicated here.

Mr. KYROS. I think that you have qualifications to talk about how much money do you think would be required for a Commission to make a study, 1 year long.

Would you have any idea about that, Dr. Simonds?

Dr. SIMONDS. Are you talking about a Commission effort?

Mr. KYROS. Yes. We talked earlier about the relative cost of having a \$50,000 conference that would last a week, a suggestion that Health, Education, and Welfare had projected of the question of studying

of epilepsy and how much this Commission would cost if you are familiar at all with what it would cost.

Dr. SIMONDS. Well, my own experience on the President's Committee on Health Education indicated that over about 18 months our costs for running the full committee of 17 members with regional hearings and several committee meetings and staff work was slightly under a million dollars.

I think, however, one has to do a cost-benefit analysis of these kinds of operations. I think that an isolated study group of experts can probably do the kind of study that's needed for a relatively low cost.

However, if this effort itself as a Commission activity is to become part of bringing epilepsy out into the open and creating a kind of awareness in Congress, awareness in the community, awareness in the country, then I think one looks at the total cost of this as part of the educational effort.

And I think probably a year-long activity like that would probably run half a million to a million.

Mr. KYROS. Well, I don't foresee that. And now I regret that I asked the question.

But that's fine, we will let that stand.

Why can't the Epilepsy Foundation of America perform this same kind of study? Do you see any reason they couldn't?

Dr. SIMONDS. Why they could not perform the total education?

Mr. KYROS. Why can't EFA perform similar kinds of function as the Commission we propose here? Do you see any reason why they could not do it?

Dr. SIMONDS. I don't think they have the resources, first of all. I think that it is going to require a new partnership between the voluntary sector and the public sector. I think that epilepsy is a public problem, and not to take responsibility for it publicly is just negligence.

I see a joint partnership indicated, rather than either sector carrying it separately.

Mr. KYROS. I agree with that.

Well, Mrs. Steitz, your article, and I just glanced at it, is certainly excellent. Why not simply continue along this way, with Mr. Autry writing articles or periodicals, to educate the public that way?

Mrs. STEITZ. Well, Mr. Kyros, so far this has been on a hit-or-miss basis. I may write an article, and Mr. Autry's magazine may publish an article, and perhaps we are reaching the same readers twice.

If you just have a few bullets, you don't want to hit the same bear twice. We have to reach a huge audience, and we can't do it on this hit-or-miss basis. It's just been—but I would defer to Mr. Autry on this.

Mr. AUTRY. You don't need to. I think it is a good thing that our magazine, with its multimillion circulation, published this article; but you have to remember that we are one magazine. There are over 4,900 magazines in the country, and how many didn't publish an article. They all reach special interest groups, and that is precisely the audience segmentation approach that anything must take, including a subject like epilepsy.

I don't think we could begin to saturate the various segments in the way it must be done.

Mr. KYROS. All right, Mr. Furman. I noticed all the things that you were doing down in Georgia. I thought they were all very good. Why not continue that way?

Mr. FURMAN. It's basically just a hit-and-miss situation, again. And of course we will continue to do those things we do well, but we are just reaching a small segment and we have miles to go before we are through.

Mr. KYROS. Dr. Gallup, what about the research, what kind of attitudinal studies should be done?

Mr. GALLUP. Well, I think there is tremendous room for further research, really.

In measuring the gap, for instance, between what people say and what they actually do, certainly one of the great purposes of surveys is the measure of change and progress in a public form program.

As our six surveys indicated, there have been tremendous changes in awareness and a decline in prejudice.

But I think we have got to dig far deeper, really, in terms of underlying attitudes.

So I would say there is a great deal to be done in this whole area.

Mr. KYROS. I notice that you have placed your study of epilepsy, your research in epilepsy, in a pamphlet which is entitled: "A Democratic Landslide in 1974."

You realize we will probably lose all our Republican members if you do this to us. We don't want to politicize epilepsy.

Mr. GALLUP. I should add we have run many separate copies of that; that was in general public interest, so we have included it with survey results in many other areas.

Mr. KYROS. Well, now, do you have any idea how we should measure progress in these attitudes, in people's attitudes as we go along? You showed in 1949 what percentage of people thought about epileptics being employed, and saw some change. But how do we measure progress?

Mr. GALLUP. Well, certainly we have to keep the same questions to measure trends, and also to develop new questions, and then to up-date these questions, too. To measure trends, measure change.

Mr. KYROS. Mr. Heinz.

Mr. HEINZ. Yes, thank you, Mr. Chairman.

I think the panel has performed a very valuable service. Your testimony will be of great use to the subcommittee in giving prompt and, I know, adequate and fair consideration to Mr. Kyros' and the subcommittee's bill. If you will note, just about everybody on the subcommittee is a cosponsor. I think, Mr. Chairman, that we are all most appreciative to you for having brought this about.

I have no questions at this time, but I would like to reserve the option of possibly submitting some later.

Mr. KYROS. Thank you.

Thank you very much. We will thank you all. It has been very kind of you to wait all day long.

Thank you for your patience, and we certainly appreciate putting all these things on record, especially the attitudes about epilepsy,

which most of us have thought about but not really formulated concretely as you have done here for us.

I think it will be very helpful, very helpful to all the members of the committee.

Thank you all very much.

Well, it has been a long and I hope productive day, and I would like to ask Mr. Funk if he would like to return briefly to summarize any viewpoints of some of the witnesses that we heard today and to add anything we can to hope to establish some kind of a national plan for epilepsy.

Mr. Funk.

#### **FURTHER STATEMENT OF PAUL E. FUNK, EXECUTIVE VICE PRESIDENT, EPILEPSY FOUNDATION OF AMERICA**

Mr. FUNK. Thank you, Mr. Chairman.

It seems to me that to a considerable extent the testimony of various witnesses today summarizes itself.

I believe that great credit is due to the committee for holding the hearings. It's been a long day. You have heard a very large number of witnesses. And I think from their testimony the summary that emerges is this:

We are dealing with a very large national problem. And that the very magnitude of the problem suggests something of the magnitude of the approaches which must be taken to find solutions. It is quite clear that we are involved with a problem that is of concern to many professions and many disciplines; many people located at different parts of the country, and with differing interests.

We have talked about the cost to individuals, to families, and to the Nation.

We have had suggestions as to fruitful areas for further exploration and for action.

I think it is quite clear that a national commission is indicated, that a national plan is indicated; that where there are plans as, for example, in the State of Florida, the plan in and of itself has contributed immensely to an improvement of the situation.

In regard to the testimony we heard from the administration, it is not that work is not going forward. Work is going forward, and in many places. And I would hope that in our testimony we paid adequate tribute to the dedication and skills of people in HEW.

We still need, however, a focal point, somewhere for all of this activity and information to come together, so that it meshes one with the other, and so that we have an opportunity to look at progress and to assess periodically what else needs doing, and to figure out the best ways of doing it.

I would like to close, sir, with a quotation from Oliver Wendell Holmes, who said: "The law does all that it should when the law does all that it can."

And I believe that, as regards the epilepsies, the time has now come to put down some more foundations, by law, on which we can build in looking toward solutions to a major national problem.

Thank you.

Mr. KYROS. Thank you very much, Mr. Funk. That's I think a very

good, concise statement of some of the things we have seen today, which were very interesting to me, and I am sure with the kind of day that we have had here—you know, that for many members of this committee, with some things that had been portending for the last 2 or 3 weeks that didn't materialize, other plans had been made, or I think more people would have been here.

But in any event I think we now have a good chance to get this bill on the floor. I want to thank all the witnesses for their patience. I hope we can make a bill for a National Commission on Epilepsy come true very soon.

The committee will be adjourned.

[The following statement and letters were received for the record:]

**STATEMENT OF HON. GERALD E. TALBOT, STATE REPRESENTATIVE, STATE OF MAINE**

First, let me state for the record my qualifications, along with my feelings as to why I am speaking out and supporting this very important, very vital and very long overdue piece of legislation, concerned with establishing a one year national commission on epilepsy, sponsored by Congressman Peter Kyros.

I am 41 years of age, and for most of my life that I can remember, I have had epilepsy. First it was petit mal and next grand mal, for which I am on medication at the present time. In my early years, my parents and I went through frustration and mental strain while my doctors, as they still do today, go through the system of checks and balances in order to come up with the correct medication to control the black out spells, or convulsions, which hamper one's everyday life, some more than others.

As a teenager, and now as an adult, I know how it feels to participate in sports, social events and programs of one type or another, always having in your mind the fact that without warning, without prior knowledge, a seizure could take you by surprise. And because of that seizure, to be looked upon as a sickness or a disease, rather than as a human being who is afflicted with a chronic nervous disorder which is still, to a great extent, not known to the medical profession or even to the epileptic.

I know how it feels to wake up after a seizure in a different time frame, after losing 5-10 hours, even a day, with no memory of what happened or how you got where you are. I know how it feels to know what would have happened if someone very close to me, knowing my condition and what to do, had not been there to help, how fatal it could have been. Not being able to tell what happened or even to justify to yourself why it happened.

I know the mental anguish of trying to live a normal life, hold a job and bring up a family, knowing that at any time some of this could be shattered without warning. In many cases this means loss of job, embarrassment, and most of all loneliness. In simple terms, it means staying scared every day of your life.

The most tragic aspect of this entire health problem, and let me stress this, is that an epileptic's hope of a cure, all their hope of knowledge, insofar as what is troubling their nervous system, ends with their medication, the pills that one takes, probably for the rest of one's life. The medical profession and the epileptic are both at a dead end.

Many thousands of Americans have epilepsy of one type or another, family, friends, relatives and neighbors. Over 20,000 people here in Maine have epilepsy, or as it sometimes called, the invisible disease, and many, because so much is still unknown, take no medication.

These are some of my sentiments, and although I don't mean to sound grim, to many thousands of Americans who have epilepsy, it is grim. Some live normal lives, some struggle to live normal lives, and some just plain suffer.

Although I speak out, many will be silent. I can understand that, but there are many people who most probably echo the statements you read above and more, for really, we are not scratching the surface, medically, morally or financially.

For too long we have put as our top priority military spending, money for roads and bridges, money to beautify our cities and landscapes, and for too long we have neglected our health problems, such as epilepsy. Our priorities are in the wrong order, and people suffer. In this case it is the patients, the

medical profession and the every day citizen. Therefore, I strongly urge this committee to pass favorably on this very necessary piece of legislation, and to further fight to make it become a reality.

I thank the committee and Representative Peter Kyros for the opportunity to be heard in behalf of this bill, in hope that it will bring to light the problems of thousands of everyday citizens who will now have a brighter ray of hope in their lives.

Thank you, and if I can be of further help, please let me know.

NBC News,  
A DIVISION OF NATIONAL BROADCASTING COMPANY, INC.,  
New York, N.Y., August 7, 1974.

HON. PAUL G. ROGERS,  
U.S. House of Representatives,  
Washington, D.C.

DEAR MR. ROGERS: I had hoped to appear personally before the Public Health Subcommittee in support of H.R. 13405 which provides for the establishment of a national advisory commission to develop a national plan for the control of epilepsy and its consequences. Unfortunately, travel plans have made it impossible to appear personally. Therefore, I am pleased to have this opportunity to submit this written statement.

As you are no doubt aware, I have been an honorary director of the Epilepsy Foundation of America for a number of years. I have also been active in promoting the cause of epilepsy through national media. And, I am the parent of children with epilepsy.

Therefore, on behalf of my own children and the estimated four million people in this country who should be provided every opportunity to enjoy normal, full, productive lives, I would urge that every consideration be given to the support and passage of this bill.

I am sure other witnesses will provide full information concerning the nationwide \$4 billion dollar cost of the epilepsies and the tragic waste of human lives and potential. I am particularly interested in the need for a national focal point for a massive public health education program which will wipe away the ignorance, prejudice and stigma which pervades the lives of persons with epilepsy.

It has been reported in the media advertising business that it takes a budget of approximately \$5,000,000 to project one single new concept across the nation to the American public. This indicates the extent and scope of the challenge we face in changing public attitudes. The commission study under consideration may well serve as a rallying point for a major effort by communicators at all levels and in all media.

Sincerely yours,

FRANK BLAIR, LHD.

AMERICAN NURSES' ASSOCIATION, INC.,  
Kansas City, Mo., August 19, 1974.

HON. PAUL G. ROGERS,  
Chairman, House Subcommittee on Public Health and Environment, Committee  
on Interstate and Foreign Commerce, 2415 Rayburn House Office Building,  
Washington, D.C.

DEAR CONGRESSMAN ROGERS: The American Nurses' Association wishes to endorse the provisions of H.R. 13405, "National Commission on Epilepsy and its Consequences Act." We share in the concern for the four million known Americans with epilepsy.

Registered nurses provide professional services in a variety of settings to the many persons in all age categories with this disorder.

Of special significance in H.R. 13405 is the attention called to balanced interdisciplinary action and concerted attention of many disciplines. We hope nursing will be included for certainly the basic and rehabilitative care, guidance and health education provided to patients, families, friends and employers by registered nurses are of great importance to the life and particularly to quality of life for these persons. School nurses have a very valuable contribution to make in helping children and their classmates adjust to the problems encountered in relation to epilepsy.

We would also encourage inclusion of a nursing representative on the National Commission. Registered nurses are frequently the primary care and liaison professional involved in the detection, guidance, teaching and rehabilitation of the patient. Therefore, through experience and education, the nurse would be especially qualified to serve in such a Commission.

To bring about the best that the social and physical sciences can offer today, there must be dynamic interdisciplinary action available to all the persons whether they be the patient or his family and friends.

The American Nurses' Association supports H.R. 13405. Continued research into the causes and treatment of epilepsy is needed.

Yours truly,

EILEEN M. JACOBI, Ed.D., R.N.,  
Executive Director.

AMERICAN MEDICAL ASSOCIATION,  
Chicago, Ill., August 20, 1974.

HON. PAUL G. ROGERS,

Chairman, Subcommittee on Public Health and Environment, Committee on Interstate and Foreign Commerce, U.S. House of Representatives, Washington, D.C.

Dear CHAIRMAN ROGERS: On behalf of the American Medical Association, I would like to submit for your consideration our comments on H.R. 13039 and H.R. 13405, the "National Commission on Epilepsy and Its Consequences Act", which we understand is now under consideration by your Subcommittee. The American Medical Association is pleased to support legislation which calls for the appointment of a National Commission to study certain aspects of epilepsy after the Secretary of Health, Education and Welfare has consulted with the Advisory Council to the National Institute on Neurological Diseases and Stroke.

We believe that the Institute should remain the primary focus of the Government's efforts against epilepsy. It is appropriate, however, that the Federal Government support this independent effort to evaluate the scope of Federal support and participation in the management of epilepsy as a public health problem. We are pleased to note the inclusion of a provision in this Act which limits the life of the Commission. This will encourage the Commission to concentrate its attentions on the current situation among epileptic patients and will bring the life of the Commission to a close after it completes its study and submits its report.

In carrying out its responsibilities, we would trust that the Commission will consult with the American Medical Association and with other concerned national organizations during the conduct of its studies and the formulation of its report and recommendations.

Thank you for this opportunity to present these views. We respectfully request that this letter be made a part of the record of your hearings on this legislation.

Sincerely,

EBNEST B. HOWARD, M.D.,  
Executive Vice President.

[Whereupon, at 5 p.m., the committee adjourned.]







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